

Exploring Rheumatoid Arthritis  
Patients' Needs in  
Shared Decision Making: A Qualitative  
User Needs Study

by

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A thesis

presented to the University of Waterloo

in fulfillment of the

thesis requirement for the degree of

Master of Science

in

Public Health and Health Systems

Waterloo, Ontario, Canada, 2019

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## **Author's Declaration**

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

## Abstract

**Background:** Rheumatoid arthritis (RA) is a chronic inflammatory debilitating joint condition with individualized symptom severity. Access to multiple medication choices allow consideration of patient preferences and fit to their lifestyles. Shared decision making (SDM) is a recent approach in medicine where medical decisions are formed in combination of latest scientific evidence, patient's lived experiences, and physician's clinical expertise. SDM may be a fitting approach for RA due to the extended time allowed for developing patient-physician rapport, room to discuss patient preferences, and decisions to be revisited.

**Objective:** To explore user needs and challenges to support RA patients in shared decision-making processes as it relates to chronic disease management, self-monitoring, and medication choices.

**Methods:** Semi-structured interviews were conducted with RA patients (n=13) recruited from the Canadian Arthritis Patient Alliance. Thematic analysis was performed using NVivo software. Data was coded inductively and iterated on until no new themes emerged.

**Results:** Three main themes emerged from interview data. (1) *Gaps in Psychosocial Care:* Relevant to short and long-term medication side effects, sexual health, mental health, and family planning were sensitive and stigmatized topics which were often dismissed at the rheumatologist's visits. (2) *Patient Agency:* RA patients were exercising patient agency needed for SDM through proactively seeking knowledge about their disease; making personal judgements on medications based on their symptoms; and relying on their social support networks for tough decisions. (3) *Adaptations:* Over years of dealing with RA, patients reported adaptations, such as flexibility to psychological adaptations, improved general health through modifiable lifestyle factors, and several minor ergonomic changes for improved daily comfort.

**Conclusion:** Designs in health technology to support RA patients with SDM may benefit by acknowledging the dynamic nature of RA as a chronic disease. Further socio-technologic developments can minimize the burden of living with RA.

## Acknowledgments

I would like to firstly thank all of the great and interesting connections who have turned into friends throughout my time in Waterloo. Your support and insights are really appreciated. Thank you to all of my friends and family on the West Coast for being there throughout my challenges. To the Games Institute and all its members, thank you for being a solid institution to support interdisciplinary students such as myself.

Thank you to the Canadian Arthritis Patient Alliance members for taking the time to volunteer and for sharing your experiences with me. This study would not have been possible without you.

I'd also like to thank my committee members. Thank you to Dr. Plinio Morita, who gave me wonderful insights from a human factors perspective and to Dr. Kitty Corbett, who I've had the privilege of seeking advice and having reflective conversations with.

Lastly, I would like to extend my utmost gratitude to Dr. James Wallace, my supervisor who helped me conduct this study, brainstorm ideas, write this thesis, and who believed in my abilities from the beginning. Thank you so much!

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## **CHAPTER 1: Introduction**

Scientific advancements in medicine and pharmacology have increased the availability of effective treatment choices for patients. Concurrently, a move away from the paternalistic model of care has shifted the patient's role from a passive to active participant in treatment decision making. An approach called shared decision making (SDM) has been gaining popularity; it considers clinical expertise, and patient preferences in the process of treatment decision making.

SDM is useful for various complex clinical scenarios. Scenarios which can benefit from patient-physician interaction using SDM include situations where there is more than one clinically relevant treatment option; and where information is unclear on treatment effectiveness and outcomes of choosing one medication over another. Another viable option, given all treatment options, is to take no action; this refers to 'awareness of clinical equipoise' (Brom et al., 2017; Elwyn, Edwards, Kinnersley, & Grol, 2000). Patient values, preferences and input add value towards the decisions made and have potential to improve quality of health care delivery. The risks, level of uncertainty, effectiveness of treatment, costs, lifestyle changes, and side effects need to be properly discussed. Patient preferences are becoming regarded as an important part of medical decision-making processes. However, SDM remains a challenge to implement into practice given the constraints, influences and multiple factors arranged in the health care system (Epstein & Gramling, 2013; Gillick, 2015).

One way to facilitate shared decision-making has been to use paper-based decision aids (Breslin, Mullan, & Montori, 2008). Paper decision aids are typically one to multiple sheets of paper containing summarized information on a disease with associated medication, side effects, and other available considerations when deciding on course of treatment. The purpose of the

decision aid is to educate patients and to guide conversations by helping patients and physicians discuss all the available options of treatment, likelihood of outcomes through numerical concepts, and associated factors, such as costs. Researchers have developed and tested digital decision aids with the aim to facilitate SDM interaction between patients and physicians (Brom et al., 2017; Li et al., 2013; Nota, Drossaert, Taal, & van de Laar, 2015; Plaisance et al., 2016).

However, further research which focuses on how digital decision aids function to support SDM is needed to build effective decision support. Drawing from a human-computer interaction perspective, the current study explored patient views of their interactions with physicians and the potential uses of a digital decision aid to support shared interactions.

We contextualized the concepts of shared decision-making and patient-physician interaction in the case of rheumatoid arthritis as a chronic disease. Decision making in chronic diseases required a different set of considerations when contrasted with decision making for acute diseases, such as blunt force trauma cases, which require urgent decisions to be made. Specifically, chronic disease management allows multiple points of intervention over a longer duration of time, compared to acute diseases (Murray, Charles, & Gafni, 2006). Thus, perhaps for chronic patients engaging in treatment decision making, patient preferences and values are more readily modified and accounted for over time.

In a broad sense, the challenges described thus far are health systems related issues (Lewis & Pignone, 2009). Although embedded complexities such as provincial health policy at the macro-level, and duration of clinical visits at the meso-level influence SDM practices, the focus of this thesis is on understanding SDM, treatment options and clinical encounters at the micro-level (Charles, Gafni, & Whelan, 1997).

The contributions of this thesis include the following:

1. Critically analyzed the SDM definition by Stiggelbout et al. (2015), in the context of chronic rheumatoid arthritis patient experiences.
2. Identified (*T1: Gaps in Psychosocial Care, T2: Patient Agency, T3: Adaptations*) as unaddressed RA patient needs that are important for SDM through thematic analysis of interview data.
3. Suggested how to ameliorate health systems-related constraints which are experienced by RA patients and considerations for DA designs to address the identified needs.

I conducted an exploratory study using qualitative user-centred design methods to identify rheumatoid arthritis patient needs through understanding the broad patient contexts for which medication decision making occurs and to understand what patients need in order to be supported further with technology or by other means. SDM was also explored to understand whether SDM is a fitting approach for chronic disease patients, such as rheumatoid arthritis.

The next chapter will be discussing literature review on: SDM; procedural definitions of SDM; rheumatoid arthritis as a chronic disease; SDM for chronic disease; and decision aids as an implementation tool for SDM.

## **CHAPTER 2: Literature Review**

Due to the complexity of implementing shared decision-making practices, three main disciplines helped frame this research. First, from a clinical perspective, understanding influences of treatment decision making on patient lifestyles with regards to the chronic disease management of RA were critically important. Second, human-computer interaction (HCI) methodology evaluated user needs and operationalized shared decision-making processes which allowed an understanding of existing procedures. Last, from a public health perspective, lived patient experiences helped better understand implications of health decisions on quality of life and wellbeing. This chapter will discuss gaps present in literature for: facilitating shared decision making given the context of rheumatoid arthritis as a chronic disease, potential limitations of the procedural definitions of SDM, and decision aids as an existing implementation tool for SDM.

### **2.1 Rheumatoid Arthritis: Chronic Disease Management**

Rheumatoid arthritis (RA) affects 1% of all Canadians and is a debilitating chronic inflammatory joint condition with multiple risk factors and lifestyle considerations that play a role in management of the disease (Wong et al., 2010). With regards to RA patient outcomes, disability and radiographic damage doesn't occur often for there to be a detectable and measurable disease outcome. Therefore, a core set of disease activity measures were developed to standardize and monitor patient experiences of pain, tender joint counts and swollen joints (Felson et al., 1993). This illustrates the chronic and subjective nature of RA, and the importance of it as a disease requiring the patient's input to offset the symptoms and experiences of pain, tender and swollen joints.

With multiple disease modifying anti-rheumatic drugs (DMARDs) available, decision-making in consideration of patient preferences, clinical outcomes, contraindications, and side effects is complicated. RA medication effectiveness has become relatively successful and advanced in the field of pharmacology; thus, areas for improvement have shifted towards management of quality of life and patient preferences. Pharmaceutical advances have also shifted the goal of therapy from ‘symptom relief to sustained remission’ (Barton et al., 2014). As described by Barton (2009), patient preference-sensitive options, such as mode of drug administration, costs, medication type, and side effects associated played a significant role in long-term chronic disease management. Moreover, patient satisfaction, or alignment of patient values beliefs, and preferences with the decided course of treatment encouraged higher adherence to medication regimens (Barton, 2009).

Previous research showed that pain was experienced subjectively and was not necessarily matched with inflammation directly observed on X-rays (Hammer, Uhlig, Kvien, & Lampa, 2017; Jensen et al., 2001). Further, beliefs of control over pain was associated with decreases in depression, pain, and patient disability (Jensen et al. 2001). Patients also expressed concern over long-term medication use, feelings of dependency, side effects, risks, efficacy and running out of future available options for symptom relief (Nota et al., 2015). The nature of RA involves a range of pain and inflammatory symptoms which are often out of the patient’s control; furthermore, as a secondary impact of living with RA, psychological and social wellbeing are impacted, limiting capacity to engage in daily activities and obligations in domains such as work; family and relationships; and leisure. (Backman, 2006). Thus, catering to individual needs and having preference-sensitive options for RA patients when deciding on a new treatment regime could potentially play an impactful role in patient autonomy and empowerment.

## 2.2 The Shared Decision-Making Model

Medical decision making is an ethical issue resulting in a range of considerations to make, especially when there is no one option that precedes over others (Epstein & Gramling, 2013). ‘Clinical equipoise’ is a term used to describe a state where no one decision is the obvious one, and where taking no action is an option (Brom et al., 2017; Elwyn, Edwards, Kinnersley, & Grol, 2000). Shared decision making (SDM) is often thought of as way to practice patient-centred care. As it is the case for RA, SDM is seen as particularly useful when there are multiple treatment options, uncertain outcomes associated, and when benefits and harms of treatment are viewed differently by patients and by physicians (Ottawa Hospital Research Institute, 2014).

SDM is defined as an “approach where clinicians and patients shared the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences” (Elwyn et al., 2012, pp.1361). SDM can be thought of as working towards two primary goals: information exchange and decision making. Many studies have investigated knowledge uptake in patients (Montori, Kunneman, Brito, A, & VM, 2017; Sepucha & Scholl, 2014). Although educating the patient is an important part of SDM, education alone is often insufficient for SDM to occur (Joseph-Williams, Elwyn, & Edwards, 2014); thus, the process must be supplemented with a two-way discussion of treatment options. Moreover, SDM includes patient education, deliberation of options, and ideally leads to a joint medical decision between the patient and physician. However, SDM is context-dependent and remains difficult to measure, evaluate and identify (Sepucha et al., 2013).

## **2.3 Shared Decision-Making Applied to Chronic Disease**

Due to the nature of disease, different considerations for SDM are needed for chronic disease, as opposed to acute disease. Differences between acute and chronic disease choices in shared decision-making can be illustrated by the differences in the urgency of decisions made and the length of time given to make a decision (Montori, Gafni, & Charles, 2006). For example, an acute patient may decide to undergo surgery and immediately face post-operative healing and recovery. On the other hand, chronic diabetic patients must constantly monitor blood glucose levels and adhere to treatment decisions made. Treatment decisions can be altered at multiple time points on a needs basis with physician consultation, and often the side effects can affect lifestyle choices, such as diet intake, or capacity to exercise (Murray et al., 2006). Since chronic disease management centres on living acceptably with the disease and on offsetting the symptoms, adherence to medication is critical.

For chronic disease management, since there were repeated and multiple opportunities to monitor and revisit patient conditions, patient preferences and values were readily modified, experimented, and accounted for when engaging in treatment decision making (Montori et al., 2006). A systematic review found effectiveness of SDM for long-term decision making (Joosten, Defuentes-Merillas, et al., 2008). Moreover, because SDM was consultative and conversational in practice, the application of SDM to chronic disease patient-physician interactions is fitting. SDM can play a vital role in patient engagement, patient empowerment and autonomy of their own life, especially given the chronic nature of disease, affecting daily activities.

## **2.4 RA Patient Concerns and Barriers to Implementing SDM**

More than 30 years has passed since ‘shared decision-making’ was coined in the report, President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (United States, 1982). In the report, SDM was recommended to become the gold standard of clinical care. Although clinical discussions on medication choices, side effects, and mode of administration occur, gaps in SDM exist when addressing patient concerns. Various patient-related factors have been found to limit the implementation of SDM.

Numerous patient-related concerns existed to shape the reality of medical decision making; these concerns may be barriers to SDM if not addressed. Often, physicians and patients may perceive the expectations, perceptions and efficiency of each medical treatment decision to be different. One reason for this may be because not all treatment options are explicitly discussed as possibilities (Brom et al., 2017; Nota et al., 2015). Specific to RA patients, DMARDs can sometimes be described as being an aggressive set of medications. Not surprisingly, some RA patients worried about the trade-offs of initiating DMARDs to prevent future joint damage and feeling doubtful of taking aggressive medication with potential side-effects such as hair loss, vision loss, and risks of developing cancer. In addition, some RA patients were anxious and concerned about ‘running out of treatment options’ (Nota et al., 2015). Drug effectiveness can vary by individuals, and therefore drug treatment was a trial-and-error process. The chronicity of the disease can also be psychologically difficult to deal with as it can affect one’s lifetime.

Similar to communication of available options, themes of mistrust in the health care system, in the physician, and ultimately in treatment decision making may act as a barrier to consultations. Townsend et al. (2013) found that some RA patients were hesitant to start DMARDs and instead, sought over-the-counter pain medication to manage arthritis symptoms. Using over-the-counter



pain medication delayed patient-physician consultation of potentially useful RA treatment options. Furthermore, an effective discussion of treatment decision making and of the importance of the medication was suggested as necessary to ensure proper medication adherence (Townsend et al., 2013).

Patient needs varied by values and preferences which were driven by subjective individual feelings. The emotional impact related to consuming the type, volume and frequency of medication can be a factor which magnify subjective feelings of illness experienced by RA patients (Nota et al., 2015). Discussion of long-term goal and treatment planning was suggested to ease patient anxiety, as the variation in symptoms experienced over time can be psychologically taxing (Gillick, 2015; Nota et al., 2015). There's also a variation in the perceived and preferred roles that patients would want to play in shared decision making. Younger patients and higher educated patients were found to prefer a more active role than other counterparts (Brom et al., 2014). Due to the varied RA specific issues, it is unclear how RA patient needs are currently being addressed through SDM processes.

## **2.5 Procedural Definitions of SDM**

Many have attempted to define the process of shared decision-making to provide guidelines for implementing SDM in the medical encounter. The milestone study by Charles et al. (1997) which brought SDM into the spotlight, defined shared decision-making by three elements during a clinical encounter: 1) that at least two participants—physician and patient were involved, 2) that both parties shared information, 3) that both parties built consensus about preferred treatment 4) that an agreement was reached on the treatment to implement (Charles et al., 1997). Although the

original model by Charles et al. had been developed in the acute setting, considerations have been made to fit chronic disease management settings as well (Montori et al., 2006). A systematic review conducted by Makoul and Clayman (2006) found a lack of consistency and ‘no shared definition’ for what constitutes as SDM. Out of the systematic review, 9 essential items were recommended in order to begin elucidating a shared definition of SDM.

Based off of the 9 recommendations, Elywn et al. (2012) further simplified the items into a 3 step-by-step guideline for practical use. The three-part model that was defined by Elywn et al. (2012) included the following: 1) choice talk, making sure that patients knew that reasonable options were available. 2) option talk, the step of providing more detailed information about options, and 3) decision talk, the step of considering preferences and deciding what is best.

Most recently, Stiggelbout, Pieterse, & De Haes (2015) added a fourth step onto Elywn’s model for engaging in shared decision making. The four steps provided by Stiggelbout et al. (2015) included: 1) The professional informed the patient that the decision was to be made and that the patient’s opinion was important. 2) The professional explained the options and the pros and cons of the relevant option. 3) The professional and patient discussed the patient’s preferences; the professional supported the patient in deliberation. 4) The professional and patient discussed the patient’s decisional role preference, made or deferred the decision, and discussed possible follow-up (Figure 2.1).

These procedural definitions of how SDM ought to be performed have been defined as a means to implement the concepts of SDM into medical practice. Historically, procedural definitions of SDM have been rooted in a clinical perspective. To date, Stiggelbout et al.’ definitions has not been studied among RA patients. Therefore, it is questionable whether the definition is catered towards RA patient needs and informed by lived experiences.

1. The professional informs the patient that a decision is to be made and that the patient's opinion is important.
2. The professional explains the options and the pros and cons of each relevant option.
3. The professional and patient discuss the patient's preferences; the professional supports the patient in deliberation.
4. The professional and patient discuss patient's decisional role preference, make or defer the decision, and discuss possible follow up.

**Figure 2.1** Procedural Shared Decision-Making Definition (Stiggelbout et al., 2015)

## **2.6 Decision Aids**

Decision aids (DAs) are digital or paper-based health information sources based on concepts of shared decision-making and evidence-based medicine. These products have been partially produced in reaction to the complexities of SDM.

DAs are intervention tools which have mainly been studied and implemented prior to medical consultation (pre-consultation DAs), and during (in-consultation DAs). The purpose of a pre-consultation DA is to increase patient knowledge and clarify patient values prior to the medical encounter. While deliberation and clarification of knowledge are partially supported through questionnaires to test knowledge acquired and to clarify patient values, pre-consultation DAs does not include the physician. There is an underlying assumption, that the pre-consultation DA will prepare the patient for consultation given increased knowledge on medication pros and cons; and probability of outcomes per medication choice. Pre-consultation DAs focused on implicitly trying

to promote an active patient role in decision making. In-consultation DAs are dependent on the patient, physician and environment; thus, the success of the DAs depended on level of patient-physician interaction and context. In-consultation DAs focuses on guiding conversations by providing scientific content to engage in, leading to eventual treatment decisions.

A Cochrane systematic review of randomized controlled trials found that DAs, compared to usual care improved knowledge of treatment options, improved decisional conflict related to personal values and made patients feel more informed (Stacey et al., 2014). Thus, DAs were demonstrated to have beneficial impacts on health care services, as opposed usual care without the aids. In efforts to standardize the development of DAs, the International Patient Decision Aid (IPDA) established a set of criteria for decision aids.

## **2.7 Paper-Based DAs versus Digital DAs**

Over the last two decades, a large emphasis was placed on producing paper DAs for a variety of diseases. Table 2.1 provides an overview of a series of paper and digital DAs. Typically, paper-based DAs are one to multiple sheets of paper containing summarized information on a disease with associated medication, side effects, and other considerations when deciding on a course of treatment. Paper-based DAs had limited reach as a medium in terms of adoption, standardization, dissemination (Holmes-Rovner et al., 2007). Paper-based DAs can do more harm than good if the information disseminated contained outdated information, whereas software updates can correct for any updates needed.

Digital DAs have similar content and intent as paper-based DAs but are digital. A systematic review found that certain features of a digital DA work better than alternative aids, or usual care (Syrowatka, Krömker, Meguerditchian, & Tamblyn, 2016). A promising advantage of

digital DAs may be the ability to address drawbacks of paper-DAs. For effective communication to occur, information must be available at the right time, right place, and right audience (Kreps & Neuhauser, 2010). As long as internet was available, there were no physical limitations to access digital DAs; thus, access to the DA was possible before, during and after medical consultation.

Digital DAs also have the potential for customization of each patient and offer the potential benefits of a centralized system with storage, monitoring, and presentation of in-depth information (Politi, Adsul, Kuzemchak, Zeuner, & Frosch, 2015). In addition, digital DAs have greater ease of quick iterative improvements via tracking usage data and gaining user feedback than paper-based DAs. Perhaps an important relative distinction from a paper-based DA may be that digital DAs enable efficient updating of new features or evidence-based literature as it becomes needed and available (Dorfman et al., 2010). Thus, digital DAs may be a knowledge translation tool that lessens the gap between the public and academic research findings.

**Table 2.1** Paper and Digital Decision Aids for Shared Decision Making

Decision Aids	Authors	Comments
<b>Paper</b>		
Decision Boxes	Giguere (2012)	-For various diseases -Patient & Clinician version -Online, but not interactive
Option Grids	Elywn (2013)	-Static pdf -For various diseases -Grid where rows are FAQ and columns are treatment options
Issue Cards	Breslin; Montori (2008)	-series of patient issues per paper card -used as a conversation guide for decision -developed for diabetes
RA Choice	Barton (2014)	-series of patient issues per paper card -used as a conversation guide for decision -developed for rheumatoid arthritis
<b>Digital (online)</b>		
ANSWER Animated Self-Serve Web-based Research tool	Li (2013)	-Aims are to start methotrexate or to discuss further treatment options with doctor -Animated clips of others' experience & education about RA. -Quiz and summary output
Option Grids	Elywn (2015)	-Online Interactive -10 min questionnaire with summary as output -for various diseases
Issue Cards	Montori (2015)	- Output summary, with E-prescription -Online interactive wizard - for various diseases
RA Navigator (prototype)	Baker; Wallace (2015)	-Online interactive -developed for rheumatoid arthritis

To our current knowledge, 5 different studies investigated the development and implementation of RA patient DAs using the IPDAS criteria as a guideline; all studies follow a user-centered design approach. Li (2013, 2009) documented the development of ANSWER (Animated Self-serve Web-based Research tool) which was designed to initiate DMARDs in newly diagnosed RA patients to minimize delayed uptake of the drug, followed by ANSWER-2 which similarly intended to help patients switch to a biologic therapy. The ANSWER decision aids used a series of patient narratives and evidence-based literature to communicate the educational health messages. A Spanish study assessed and developed a DA for moderate to severe RA patients. Specifically, the purpose was to support patients with decision making when switching medications and where their initial DMARD therapy failed to achieve symptom stability (Pablos et al., 2019). Similarly, Brinkman (2017) developed and implemented a DA for facilitating SDM

with parents of children with juvenile idiopathic arthritis. In particular, the focus of the DA was on starting or switching DMARDs and biologics. A low-literacy DA, *RA Choice* was developed for 3 languages among RA patients with moderate to high disease activity. It was designed to communicate medication options based on evidence and meant for in-person clinical consultations (Barton et al., 2014). Nota focused primarily on patient concerns, such as long-term and short-term side effects, when deciding on DMARDs, and later developed a DA with both input from patients and physicians (Nota et al., 2017; Nota, Drossaert, Taal, Vonkeman, & van de Laar, 2014). Upon review, most current RA DAs focus on newly diagnosed RA patients, patients needing to switch medications, and focus heavily on communicating medication options.

Most DAs didn't necessarily account for the long-term planning and goal setting needed in chronic disease management. Out of the 5 different studies to date on RA DA development, only two mentioned psychological and lifestyle considerations as important and relevant patient user needs required for SDM (Nota et al., 2014; Pablos et al., 2019). Further, no current decision aids have been published which offer functions to elicit or support lifestyle factors and psychosocial needs as it relates to RA medication decision making. The RA DAs discussed focus on medication options and are often constructed as discrete choices to make as part of SDM; however, chronic illness DAs should be designed for multiple decisions over a long time (Matlock & Spatz, 2014).

Malm et al (2019) discussed the importance of integrating lifestyle habits as part of the physician visits; however, as the study found lifestyle habits weren't being discussed often. Perhaps, discussions on lifestyle habits are a potential opportunity to improve long-term outcomes in RA. Furthermore, a need to individualize treatment plans to subjective patient experiences was found in a study by Baker et al (2019), where different preferences were found on either preventing long-term joint damage while on DMARDs and dealing with substantial side effects; versus

discontinuing DMARDs and living a ‘normal’ lifestyle with no side effects. Overall, information regarding individual lifestyle preferences, comorbidities, and chronic disease management strategies as it affects medication decisions have not been the focus of study for RA DA development.

## **2.8 Where Current Research Falls Short**

Due to the lack of research around how DAs holistically support those with RA, our study aimed to explore existing practices and patient views on SDM, SDM applied to chronic disease, and how DAs can support RA as a chronic disease. Overall, our study rationale was to understand SDM from the perspectives of chronic RA patient experiences to elucidate patient needs and attributes which contribute to how health decisions are made.

We sought to explore ‘why’ and ‘how’ questions to explore what hindered or promoted SDM for RA patients. Moreover, we gathered an understanding of user needs in the complicated process of SDM applied to the context of RA. Gaps in knowledge existed in whether and how SDM can support RA as a chronic disease; specifically, we sought to investigate RA patients’ needs and how patients make decisions in order to inductively assess how to build supportive decision aid tools for them. The study contributed by understanding how SDM was currently being practiced, how it could be improved, and which barriers existed for conducive communication of patient concerns. From the study findings, we then aimed to explicate a series of suggested improvements for RA patient health.



## **CHAPTER 3: Study Design and Methodology**

The purpose of the study was to understand RA patients' needs and perceptions which contribute to how health decisions are being made to manage their chronic disease. In addition, the perceived role of RA patients in shared decision making, as defined by Stiggelbout et al. (2015) was examined.

### **3.1 Research Questions**

#### *Understanding User Concerns and Needs*

What are the needs and attributes of rheumatoid arthritis patients and how do attributes contribute to decision making processes?

#### *Supporting User Needs*

How can technology, such as decision aids, support rheumatoid arthritis patients with shared decision making defined by Stiggelbout et al. (2015)?

### **3.2 Methodology**

Gathering user needs is essential to building useful technology and is one of the key facets of user-centred design. User needs include information from users' experiences which would help to eventually promote greater ease of use and adoption of technology. To answer the research questions, understanding the nuances in patient experiences was necessary because decision-making processes from a chronic RA patient's perspective was overall contextual and situational. Furthermore, uncovering the context of RA patients engaging in decision making may lead to improvements on existing DAs to support patient needs.

### **3.3 Study Design**

The study design employed was an exploratory qualitative methodology, largely due to the study's objectives of understanding and gathering user needs and perceptions. Qualitative approaches were most suitable to address "how" and "why" questions about improvements to make in shared decision-making processes. The aim was to uncover the nuances and processes that are currently working to promote patient-physician shared decision-making in medical consultations, and to gather information in areas that could be improved. Ethics approval was granted by the University of Waterloo's Office of Research Ethics (ORE # 22573).

### **3.4 Participant Recruitment**

The eligibility criteria for patients included those who: have been diagnosed with rheumatoid arthritis, are a Canadian resident, spoke English, and had encountered speaking with a rheumatologist at least once before our study. Patients were recruited from the Canadian Arthritis Patient Alliance (CAPA) (n=13) between January and April 2018. CAPA is a national non-profit volunteer run network which fosters a community based on RA patient empowerment, advocacy, knowledge dissemination, and research collaborations. Rapport was built and maintained with CAPA Committee members and recruitment emails were distributed to members via mailing list, in search for volunteer study participants (Appendix A2). Using the national CAPA mailing list for recruitment ensured adequate number of Canadian participants diagnosed with RA and with a similar exposure to resources and background knowledge.

Key informant interviews were conducted first to gather an understanding of the appropriate context and questions for our sample. Next, the interview guide was minimally altered to reduce redundant questions, was confirmed to be useful for gaining rich insights and was used for remaining participant interviews. Upon completion of the study, findings will be distributed back to the RA community through CAPA.

### **3.5 Participant Interviews**

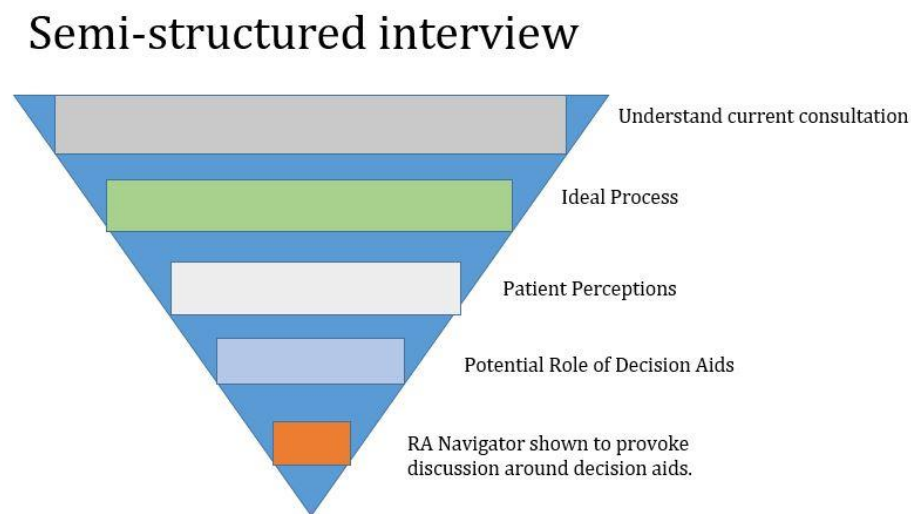
Interviews drew on RA participants as experts of their lived experiences with regards to decision-making encounters. Skype and Facetime was used as the online platforms for conducting interviews as most of our recruited participants were outside of the local region.

Interviews were approximately 45 minutes to an hour in length. Informed consent for participation was obtained as well as permission to audio-record the interview for accurate transcription in later stages. Participants were provided with 10\$ as remuneration for participation.

The general aim of the study was explained to participants, basic information regarding patient age, sex, age at diagnosis, and current medications were obtained. The semi-structured interview guide (Appendix A1) was designed to answer both research questions to: first, capture existing consultation processes by asking participants to reflect on the most recent rheumatology visit; second, to gain perceived ideal processes (what they imagine could be different); third, to gain RA patient experiences with disease management; fourth, to understand patient opinions on DAs; and finally, a digital DA prototype, *RA Navigator* was shown to provoke discussion on DAs (Figure 3.1). The interview questions were centred on the idea such that there were many possibilities for how improved communication between a patient and physician can look like

(Kahn & Cannell, 1957). Participant data were collected until saturation, saturation referred to when no new themes or evidence was identified from the interviews.

Through Key Informant 2, we were able to connect to and interview a pharmacist who specialized in RA patient counseling. Insights were gathered on the pharmacist’s perspectives on RA medication decision making among RA patients; however, we did not include the interview in our analysis due to lack of time and there being only one pharmacist interviewed to draw insights from.



**Figure 3.1** The interview guide included a series of semi-structured interview questions which was composed to answer research questions 1 and 2.

### 3.6 Thematic Analysis

Data was analyzed through latent inductive thematic analysis using QSR International’s NVivo 12 from an essentialist, or realist epistemology to analyze the data (Braun & Clarke, 2006). This interpretation of data matched our analytical goals, which was to explore insight from lived patient experiences of SDM; the realist lens sought to “report experiences, meanings and the realities of participants.”(Braun & Clark, 2006, p. 81)

Semi-structured interviews were audio-recorded, transcribed verbatim, familiarized by reading all transcripts multiple times, segmented into meaningful units, and initial coding was conducted and revised as needed. The theme code sets were developed based on the interview guide (Appendix A1) and were generated from the interview data. The theme codes were modified and refined iteratively as subtle differences were realized from the interview transcripts.

To understand data in greater depth, thematic maps were produced (Appendices B1-B3) and contextual factors were considered over multiple passes through the data. The first pass considered differences between patients who were worse off in managing their RA symptoms, compared to those who were minimally affected by their disease. (Appendix B1). Fewer areas of intervention were found in RA participants with minimal RA symptoms as they were able to maintain a similar lifestyle as before their RA diagnosis. The second pass considered how participants interacted with their physician and navigated the health care system (Appendix B2). Furthermore, by clarifying which patient needs were being met by the physician and the health care system, unmet patient needs were made clear. Specifically, psychosocial factors as it related to RA medication choices, such as mental health, sexual health, fertility in males, and pregnancy were topics which were not often discussed in the physician's office.

Analysis from Pass I and II allowed for a comprehensive understanding of existing structures and norms in patient experiences to provide greater analysis of the context behind RA decision making. The overall context of RA patient decision making was clarified with five broad contextual factors that led to understanding and exploring the three main themes (T1, T2, T3) from our study (Table 4.2). Time constraints of a 10 to 15-minute appointment was also a common concern for patients when asked about their opinion on shared decision making. Finally, given the

conceptualization from the first two passes, and contextual factors, the third pass incorporated time constraints as a systemic barrier to achieving shared decision making (Appendix B3). As described further in Appendix 3, areas to improve patient needs were made clearer.

Three data-driven themes were identified: (T1) Theme 1 Gaps in Psychosocial Care; (T2) Theme 2 Patient Agency and; (T3) Theme 3 Adaptations.

## **CHAPTER 4: Results**

### **4.1 Patient Demographics**

Semi-structured interviews were conducted on patients over Skype with exception of one participant who was interviewed in person (n=13). One pharmacist was interviewed as well to gain perspective on the interaction between RA patients and pharmacists (n=1). Patients were interviewed between January and April 2018. The average patient age was 59.75 years old. Patient 9 had been excluded due to audio recording issues; the recording was not reliable enough to be included in the analysis. Patient 7 was partially included due to audio recording issues. The pharmacist was excluded from the analysis as one pharmacist may be inadequate to represent the views of most pharmacists. Table 4.1 displays patient demographics; age at diagnosis, age, occupation, gender, and state of condition.

**Table 4.1** Patient Demographics, Interview Data from January-April 2018  
 KP = Key Patient Informant, P= Patient

Patient ID	Years of Diagnosis	Gender	Age	Occupation	State of Condition
KP1	9	F	62	Healthcare research	Controlled with minimal side effects
KP2	11	F	43	Works for RA non-profit, works from home	Mainly controlled, some fatigue and limitations
P1	2	F	55	Nurse in hematology	Condition not controlled, other comorbidities present: (deep vein thrombosis, pulmonary emboli), pain management
P2	1	F	58	Shift work for 35 years, did not specify	Newly diagnosed
P3	2	M	69	Retired farmer	Mainly controlled with some lifestyle limitations
P4	37	F	69	Former nurse	Experienced patient with controlled condition
P5	32	M	50	University professor	In wheelchair with many joint replacements, RA is not the main health priority
P6	10	F	58	No data	Controlled condition, in remission, sclera derma
P7	36	M	71	Part time consulting	On biologic therapy (implied controlled condition)
P8	15	F	65	Was working part time but quit to be husbands care giver	Controlled condition with biologics
P9	16	M	65	Works/ worked in IT	Inaudible
P10	30	F	60	Nurse in long term care	Controlled condition with pain medication, RA progression halted for now
P11	34	F	57	Involved in non-profit for RA	Has 14 joint replacements, disabled
P12	N/A	F	N/A	Pharmacist	N/A



## 4.2 Thematic Analysis

**Table 4.2** Concept and Definition of Contextual Factors from Interview Data

Concept	Themes that branched out from concept	Definition
<b>Existing Rheumatology Visit</b>		
Usual Consult Procedure	Theme 1	Standard procedures for a 10-15 min appointment
Health Assessment Questionnaire	Theme 3, 1	Standard questionnaire on quality of life and daily functioning
Patient-Physician Dynamic	Theme 1 2	Interaction and ease of communication between patients and physicians
<b>Chronicity of RA</b>		
Complexities of RA Drug Choices	Theme 1 2 3	Individualized disease; considerations for side effects
Quality of Life over Quantity	Theme 1, 2	Quality of life with medication vs. longevity of life
Patient Fears	Theme 1, 2, 3	Switching medications, expectations of maintaining lifestyle and hobbies
Comorbidity/ Multi-morbidity Needs	Theme 2	Coordination with other specialists and considering drug interactions
Long term goals (positive connotations)	Theme 1,2,3	Remission as an ultimate long-term goal to achieve, other personal goals
Long term outlook (uncertainty)	Theme 1,2,3	Uncertainty in future disease progression
<b>Drugs &amp; Side Effect Management</b>		
Managing time, energy, priorities	Theme 1, 2, 3	Management of daily activities, chores, and social relationships
Switching Medications	Theme 1, 2	Trial and error of drug combinations to achieve right balance of drugs
<b>Health System Barriers</b>		
Care Coordination	Theme 1, 2	Coordinating lab results, information between specialists, ensure there are no drug interactions
Scheduling	Theme 2	During times of flare-ups, a predetermined appointment is not enough, need for drop in
<b>Monitoring &amp; Assessments</b>		
Self-Monitoring, Journaling, Apps	Theme 2, 3	Tools to help patients become aware of symptoms

### **4.3 Gaps in Psychosocial Care (T1)**

Psychosocial factors included both psychological and social dimensions of living with rheumatoid arthritis (Backman, 2006). In rheumatoid arthritis care, more emphasis is needed on reducing negative impacts of disease beyond preventing joint degradation and reducing inflammation and pain. RA symptoms and side effects often limit daily activities and quality of life. As a result, RA disease management tended to include prioritization of daily tasks and management of energy and time (eg: choosing between cleaning the washroom vs. visiting a family member), in addition to managing medications, side effects, and symptoms. Over time, living with RA prompted lifestyle adjustments to social expectations, to activities of daily living, and to psychological hindrances can affect a patient's overall wellbeing and health state. To supplement RA patient counseling, which often covers chronic disease management, pertinent psychosocial topics that are currently not offered need to be addressed.

Findings from the current study reveal that mental health, sexual health, and family planning are topics that are rarely discussed in the context of a RA patient-physician interaction. The following sections will discuss the psychosocial needs of patients in greater detail.

#### **4.3.1 Mental Health**

Mental health plays a large role in dealing with a chronic illness; managing RA is a lifestyle change which can be a challenge to adjust to. Long-term cumulative effects of managing a chronic illness can be especially prevalent in those who have a complicated case of RA; it's evident through interviews that health concerns extend beyond symptoms, drugs, joint count and physical functionality. As a potential result of poorly addressed mental health care needs in rheumatoid

arthritis patients, stigmatization and lack of awareness among RA patients and those that interact with them are observed through interviews.

Patient 8 mentions social isolation, managing symptoms, and the difficulties with social perceptions of what RA is.

*“Umm, well before, you’re in complete—its almost depression because you just you’re so tired, you become solitary, because you cannot do anything. If you’re working, just do work, you come home, and that’s all you do. Its its very difficult. And, I think people; its like that old ad, if people look at you, and you look ok but what’s inside, they don’t know how you’re feeling. So, you know, they go, well you look okay, you should be able to do it, but they don’t realize how much pain people are in.”* (Patient 8)

Interviewees reported two main forms of stigmatization among RA patients. Firstly, there is a misconception of rheumatoid arthritis being similar to other forms of arthritis, such as osteoarthritis. Rheumatoid arthritis is an autoimmune disorder which affects the body systemically and therefore treatment and side effects are often systemic; whereas other types of arthritis tend to be localized to an area of the body where pain and inflammation are experienced, and treatment is targeted. Patient 8 describes their encounter with public misconceptions of RA.

*“I think the most um, with people, people think, ‘Oh you have rheumatoid arthritis; it’s just arthritis’, but I don’t think they realize that rheumatoid is such a crippling disease.”* (Patient 8)

Secondly, mental health stigma against those living with RA is also problematic as it’s rarely addressed fully by physicians and there are currently very few options for RA mental health. Patient 11 describes the dire need for mental health in rheumatology care, the effects of struggling with RA for more than two decades, and mental health as a topic which was always dismissed.

*“Um, I think the only thing that’s really lacking...umm, with most rheumatology care and people who I speak to, is uhh....issues around mental health, and uh you know, post-traumatic stress and the mental health issues of dealing with disease for 20 plus years and the impact it has on patients and the access to, you know, ‘how are you coping, mentally?’ and you know, psycho-socially, with this disease and that’s kind of always been dismissed and never really talked about and I’d really like to see that changed.” (Patient 11)*

RA is viewed as an ‘invisible illness’, and an ‘old person’s disease’, where pain is not physically apparent in the latter and, illness is not easily recognized in younger adults in the former. Thus, RA is not socially recognized or validated often. In one case, the lack of awareness for RA as a debilitating disease resulted in Patient 10 facing workplace discrimination. Patient 10 recalls wearing a wrist brace in the workplace was seen in a negative light, hinting at the potential for being called out as different, or unable to do the job.

*“And even now, they look and say, ‘oh, you don’t have ...’ like if they don’t see something, you don’t have it. Unfortunately, it’s like mental illness, this and that. ‘You’re too young to have arthritis’. Like, no there are different kinds of arthritis and I end up teaching people about it, which I don’t mind doing.” (Patient 10)*

*“Yup, taking your medications for either pain control or reduce um joint damage, or work. A lot of arthritics don’t want their employer to know that they are arthritic, because they don’t want them to be saying, ‘you can’t do your job’. (inaudible) holder wrist brace sometimes, and it’s, ‘oh, why are you wearing that? Are you okay?’ So, again it’s seen as a negative. I know workplaces are supposed to be more receptive to this, it’s considered to be a disability.”*

(Patient 10)

*“But...you don’t want to center yourself out as being different.” (Patient 10)*

### **4.3.2 Sexual Health**

Sexual and intimate relationships are greatly impacted by RA, like other aspects of daily living such as sleep, eating, or mood. As a result, factors such as pain and fatigue become primary symptoms to minimize or control. A gap in the current system exists in providing answers to questions around sexual health and RA within physician culture and standard practices. Although

medicine is geared towards symptomology and medication, sexual health needs to be acknowledged as part of holistic care practices within the context of RA patients. As RA patients have expressed, there is a sense of abandonment, or disregard of topics around sexual health as most doctors are not trained to address this part of the disease; it posits the question of the extent to which doctors are responsible for health-related quality of life dimensions of well-being. Physical fatigue, pain and mood as a result of dealing with RA, are all factors that directly contribute to lack of sexual intimacy in relationships.

Interview 10 describes the need for pain control and how pain affects multiple dimensions of daily living, including intimacy, family structure and relationships over a long period of time.

*“Probably if you’re in pain and you’re going to someone for pain control, yes. Because being in pain as an arthritic? It affects you 99% as to your daily living, um your family structure, your partner in a relationship, it’s actually intimately.”*

*“It would affect your work, your sleep, your eating, um how you interact, if you’re chronically in pain, you may not be the nicest person to be around.”* (Interview 10)

Lack of sexual health resources inhibits the ability to exercise patient agency to further better the condition. Key Informant 2 acknowledges that as a 32-year old adult, sexual health is still a large part of life. In addition to a lack of books published on RA and intimacy, the physician was unable to answer questions on how to improve sexual health and RA.

*“The um, and so the sexual health part, that does deal with some of the side effects, your medications, and just you’re so tired all the time, and all of those things, and so um, I’m not sure that there are a lot of resources out there for that type of thing either. Um and it’s not an area that anybody’s done a lot of work in, right? So, there a few books on like, you know, on intimacy and RA. But they didn’t...I mean this all stems from my fatigue right? I’m like 32, I’m exhausted all the time, and I’m not that old, right? (laughs). This is a big part of my life. He just shot me down, he just couldn’t help me with that.”*  
(Key Informant 2)

Given that sexual health is being dismissed in most current consultations, Key Informant 2 notes that health concerns affecting wellbeing and quality of life need to be addressed to work towards holistic care practices in rheumatology. While sexual health is a sensitive and stigmatized topic, more efforts are required to address the issue as a patient need.

*“So honestly, it just kind of got tossed to the side, almost. Um, like A) this is not something that hes going to talk about, and B) it was just obvious that he just didn’t have anything that he could help me with, and so it became...and so he was almost embarrassed by that kind of conversation...because he didn’t have an answer for me, he didn’t have resources for me. And, I think that’s not that different from a lot of other patients like. Our rheumatologists tend to be very good at telling us they could help our specific disease symptoms, the physical symptoms, but often anything outside of that, with like mental health, or um sexual health, um there’s huge gaps there. And that’s not part of their training, and so I know that would be helpful to...I don’t know how you change that, but I thought I’d put that out there. It’d be helpful if that could be a bigger part of the discussion. Because its...I mean obviously the physical disease impacts you greatly, but fixing that doesn’t necessarily fix all the other things that its impacted. So, that does circle back to the whole quality of life thing.” (Key Informant 2)*

### **4.3.3 Family Planning**

Family planning is a pertinent topic for discussion when selecting medications; it is evident that long-term planning needs to be considered as it relates to pregnancy and male fertility. Male fertility is a topic that must be discussed more often with men diagnosed with RA. RA is more prevalent in the female population, but it is equally important to tailor messages from a public health standpoint and patient empowerment perspective to incorporate family planning and long term prospects for male populations thinking of starting families. As described by Patient 5, perhaps being aware of long-term side effects of taking methotrexate may have better informed his choices and family planning strategies.

*“And um, you know, methotrexate has some serious fertility problems for males as well actually. And um none of that stuff was ever discussed. They’re some pretty nasty drugs to be putting somebody who is 19 years old on and not explaining to them that in the future it may impair the ability to have children and stuff like that.” (Patient 5)*

As Patient 4 confirms, at the time she was concerned about the effects of taking methotrexate while pregnant.

*“Oh yea. I was really worried you know because I didn’t know what methotrexate would do to a fetus and you know, so very concerning.”*(Patient 4)

#### **4.4 Patient Agency in Shared Decision Making (T2)**

Patient agency was used to describe the ability to make decisions based off personal experiences and judgements as it pertains to one’s lifestyle. To inform RA medication decision making, further time was required outside of the rheumatology visit for patients to employ patient agency and gain clarity over the best medication choice. To clarify the best choice, patients engaged with social support networks, proactively sought knowledge through different mediums, and learned through personal lived experiences with RA. As Key Informant 2 emphasized, there was time to search for information and multiple discussions to be had before a medical decision was made.

*“...it’s not a ‘you need to decide this right now’, for some people, it might be. But, generally there’s a couple of discussions before that happens. Um, and then honestly, people will go out of there and dig up whatever information they can.”* (Key Informant 2)

As encompassing facets of patient agency, social support networks, personal judgment and proactive knowledge seeking behavior in decision making are discussed in the sections below. Together, as observed in interviews, the three facets built patient agency in RA participants needed for an informed active participant in shared decision making. Perceptions of SDM were also explored and discussed as a related component to patient agency.

##### **4.4.1 Shared Decision Making**

Shared decision-making was generally well-supported as an approach by patients and their values and experiences as evidenced by the interview data. Patients saw shared decision-making as being a discussion supported by the doctor with clinical input and the patient with input from lived illness experiences; together, a consensus would be reached on a medical decision; and the best option available would be chosen. However, interviewees identified two obstacles to shared decision-making in practice: time and a lack of information.

*“Oh, what it means to me? Is that...you know, I’m that person with the disease, I have a fair amount of knowledge of the disease, lived with it for, you know, 30 years. I know my own body and how it reacts to different things that are happening in my environment. So when I go in to talk to my doctor, I feel that you know, it is time for a medication change. If the medication’s not working, that together, we’re going to discuss, you know, the options that are available for my next medication choice. And then we’ll decide together on what the best option is based on, you know, my doctor’s knowledge, but also my knowledge and my lifestyle.” (Patient 11)*

Under current standards, most patients have consultations that only last up to 15 minutes. Patient opinions on shared decision making were overall positive, but perhaps not practical given the current system’s constraints. One popular opinion has been the effect of shared decision making on time and cost to administer and ensure patients are well-informed.

*“I think it’s effective on two levels. I think it gives the client back some control, in their disease process, and it gives the physician (pause). It gives the physician umm (pause) it reduces the liability on the physician, if the physician has allowed the patient to make the choice. That would be my feeling on the subject. Um, the biggest obstacle to effective shared decision making is time and cost.” (Patient 1)*

SDM was suboptimal for some participants. Patient 1 recalled their first rheumatology appointment, and explained that because of the pain experienced, she wouldn’t have been capable of engaging in shared decision making. The quote highlighted an instance when SDM may not be suitable, or useful. As a chronic disease which spans years, it’s very possible that the patient-physician dynamic may evolve or may need to cater to changes in patient needs.



*“But, I remember quite profoundly, by the time I was staggered into her office, I could hardly even walk, and she was very good at, you know, ‘this is what you need, blood tests, you need to have this examination done before you can start your methotrexate, and I’m going to give you a shot of Depo-Medrol for pain relief.’ And that was so, she very much dictated how the first appointment went, but in reality, I was so sick, I wouldn’t have been capable of processing a lot of information at that point.” (Patient 1)*

As a newly diagnosed patient, Patient 3 expressed that he still needed to familiarize with the RA disease process; although shared decision making is seen as an important approach, new patients like Patient 3 may rely more on the rheumatologist earlier on in the diagnosis for knowledge.

*“Yes. I’d say yes, it’s really important. Um, we rely on, in this case because he’s a specialist, you really rely on the—and it’s a new disease too, you do rely on your specialist um primarily and he’s working with you from a basis of having a lot more knowledge about it than you have.” (Patient 3)*

#### **4.4.2 Social Support Networks in Decision Making**

Social support networks were leveraged to gain more experiential knowledge; as described above, the process to collect knowledge took time beyond the physician’s visit. Participants described a range of social support types to inform the decision-making process, including personal relationships, group sessions, and interactions with the pharmacist.

Personal relationships supplemented patient-physician interactions through providing emotional support and validation with decision making. Having insight into the opinion of others—whether it be a spouse, or an experienced peer with RA—provided supportive deliberation of information when considering medication choices. Time for deliberation of choices and

emotional support in patient counseling may be an area lacking in patient-physician encounters for which social support may be able to fulfill.

Given the uncertainty in RA management and in medication decisions, RA patients relied on family and friends for support on decision making. Patient 2 explained finding an alternative medication option through her friend, which led her to try the DMARD, Plaquenil.

*“Um, I basically had to request and had to do my own research into getting the Plaquenil, and the reason that I went that route is only because I’ve got a girlfriend who also has RA. And the Plaquenil, actually put her into remission” (Patient 2)*

Having a partner to assist with difficult personal decisions, gathering information, and to gain a second opinion were valued by Patient 3. Patient 3 also received help from his partner when injecting the medication.

*“Umm, she’s mainly in an advisory capacity. It’s nice just to have a partner, when you’re going through something like this, uh you get a second opinion on things.” (Patient 3)*

*“Or uh just discussing what your illness is and what you should do about it, so her help is invaluable in that respect plus she’s fairly well read, way better read and experienced with medical matters than I am. So her advice is always very helpful.” (Patient 3)*

*“It is quite an inconvenience because once a week you have to be injected with methotrexate. And um, right now, my wife does it for me.” (Patient 3)*

Validation and corroboration of information received from the rheumatologist’s office to information learnt from other patients and information sources were an important aspect to Key Informant 2. Key Informant 2 also commented on making the right decision given the time constraint.

*“Cuz once you leave the rheumatologist’s office, like you’re really inclined to look up information, talk to other people about it, and if they don’t reinforce what happened in*

*your rheumatology visit, that can be a big deal.” (Key Informant 2)*

*“Exactly. Yea, you want reassurance that you made the right decision and you don’t have much time, so all those things, right?” (Key Informant 2)*

Group sessions provided the opportunity for RA peer-to-peer interactions. For example, lived experiences with symptoms, patient advocacy, medication effectiveness and lifestyle changes can be exchanged. Potential benefits to regular patient support groups may be able to fill a gap that personal relationships, or rheumatology care on its own would not foster.

One participant took part in a group session; in particular, Key Informant 1 recalled one person who was hesitant to take medications despite experiencing pain; the group dynamic helped to exchange personal stories between group participants.

*“There was one person in particular, clearly in a lot of pain, but refusing to go on medication. And so part of that dynamic was to...was for me to talk to her and talk about you know, I decided to go on the medication, and I felt it made me feel so much better. And to tell her that story helped her make decisions. I don’t know what decision she ultimately made, (laughs), but there was kind of that group process going on and group dynamic that was important. That really helped me understand that, you know, arthritis is not a cut and dry thing. It’s not something that you...there’s kind of a course of action, course of treatment, your doctor prescribes it, and that’s what it is. There are many variables that play into it, and um yea. I know my own body better than my doctor does.” (Key Informant 1)*

Pharmacists may be an overlooked and important role in the medication decision making process. The interaction between the pharmacist and patient is another potential opportunity for patient counselling, or discussion about medication side effects. Although as Key Informant 2 noted, consistency across health providers with regards to health messages would be important to assist with medication decision making.

*“I think it could be reinforced at the pharmacy, because often times well there’s a hesitation to get the prescription anyway. And then when you go to the pharmacy to get it filled, you ask your pharmacist questions about it, because they are experts in the drugs, and depending on what you hear, that can totally change what you just talked about in your rheumatology visit last week, or whatever it was, right?” (Key Informant 2)*

#### **4.4.3 Personal Judgement in Decision Making**

Part of RA self-management is patient autonomy. Small but significant health-related decisions are made through exercising judgements based on personal experiences. For example, noticing body changes and deciding to stop biologic medication in exchange for DMARDs was one way that patients were making daily decisions for themselves. Many instances are highlighted through interviews where RA patients evaluated and enacted important medical decisions affecting their body.

Currently, exercising is beneficial for RA patients and is encouraged, but in previous years, Patient 7 discussed going against medical advice and had kept exercising when it was discouraged in the medical community at the time. Autonomy is exhibited through personal decisions being made; patients base their actions on their own judgements and experiences.

*“Also their frustration at a, I guess with me, (and with my wife?) I’ve always been...I’ve always exercised even through (inaudible) I’ve still kept trying to go for walks, and go to the gym, those kinds of things. And...during the initial years, like 30, 35 years ago, uh that was uh that was considered to be contributing to the effects of my disease so (inaudible) doctors just wouldn’t keep interested in me because I wanted to keep exercising.” (Patient 7)*

Biologic medications work to suppress inflammatory responses, but also weaken the immune system and lead to increased susceptibility to infections. Thus, halting biologic medication for a period and switching to antibiotics is a strategy that many RA patients need to decide for themselves. Independent patient judgement and decision making were observed as part of RA chronic disease management as evidenced by Patient 11:

*“So I have to, you know, try to judge, you know, am I feeling to the point where I need to call my family doctor, to find out if there’s more going on? Um, do I need to stop my biologic? Should I take it? You know, do I need to end up getting antibiotics? And then when to restart the medication, is another issue. You know, he will kind of give me some guidance on that but ultimately I have to decide if I’m feeling well enough, if I think the antibiotics are working well enough, and um starting the antibiotics isn’t going to cause any more problems.”*

*“It’s like the same thing post-surgery. I’ve had joint replacement surgeries. So, it’s always kind of been up to me to decide when am I gonna restart biologics, with the risk of infection is low. Nobody really tells you that. And I have to gauge it on your own.” (Patient 11)*

Self-monitoring of symptoms and noticing body changes and its interaction to drugs was an important skill that developed. Key Informant 1 described changes to inflammation levels and deciding when to temporarily stop or revert to regular medication intake.

*“So, you know, missing it for a week, or missing it for a couple of days, or you know, changing the schedule doesn’t seem to make any difference. But it’s if I do that for a long period of time, then it starts to build up, then I start to feel uhh, the inflammation coming back. And then I know that it’s time to get more regular with my medication.”*  
(Key Informant 1)

#### **4.4.4 Proactive Knowledge Seeking Behavior in Decision Making**

The desire to learn more about RA by proactively seeking knowledge to improve the condition was apparent in interviews conducted. Interestingly, forms of knowledge seeking behavior were not limited to online resources; patients described health practitioners, the Arthritis Society, and Lifelabs for blood results as sources of information.

*“Umm, so basically it was just going over the information, looking up Plaquenil in the book that the Arthritis Society have me, researching Plaquenil on the computer, and contacting my eye doctor on my own because one of the main side effects, of course is retinol issues with that particular med. And I just want to let you know, because I’ve already gotten the issue with my eyes that that was something that he was in agreement to my trying. And I’ve got his full support. Then I got back to the rheumatologist and said, ‘I would like to try this’.” (Patient 2)*

*“So, you start to have a conversation about the decision at the rheumatology visit, but then you go out and do whatever research, and homework, before they come back.” (Key Informant 2)*

*“Yea, so. Um. I recently-- Lifelabs has made it possible for you to look at your own blood work results. I find that really helpful, so I just log into the website, and I can see my own blood work results and how they change from, you know, month to month. So I find that really instructive. I’m always on the look-out for more information...” (Key Informant 1)*

#### **4.5 Adaptations for Rheumatoid Arthritis Self-Management (T3)**

To minimize the burden of RA symptoms and drug side effects, coping mechanisms were developed to better manage daily activities; medication, in conjunction to lifestyle changes were needed to control RA. For example, an RA patient may need to find the medication with the least side effects, switch careers to limit repetitive physical movements, incorporate more physical exercise, and may have to adjust expectations of their daily capacity, as compared to life before RA.

Despite initial physical and mental challenges, participants exhibited adaptability to situations and tasks over time. Physically difficult tasks were bypassed with simple alternative approaches such as, using a tool to open jars instead of relying on wrist strength. Similarly, psychologically, some participants dealt with the anxiety of future disease prognosis, and unpredictability of symptom onset by incorporating a mindset to accept the disease.

Symptom monitoring was mentioned in interviews in the form of journaling and app usage. The intention to assist RA patients in becoming experts of their own body and developing coping mechanisms through reflecting on collected data is an important consideration. However, interviews indicated that symptom tracking was only useful for frequent, pronounced symptoms in patients with an unstable RA. Further, a lack of satisfaction with app usage was reported in interviews.

Three key adaptation strategies were revealed in the current theme: flexibility to psychological adaptations, improved general health by addressing modifiable risk factors, several physical accommodations, and self-monitoring strategies.

#### **4.5.1 Flexibility to Psychological Adaptations**

Psychological adaptations to circumstances brought on by the RA lifestyle was a coping mechanism observed through interviews. Initially, changes to accommodate RA were reported to be very difficult, especially if RA compromised their ability to participate in previous hobbies which were part of their individual identities. From the interviews, two beneficial mindsets to incorporate emerged: acceptance of lifestyle changes due to RA while setting realistic expectations for oneself; and accepting the fact that RA is unpredictable and outside of the patients' control.

A flexible mindset was vital to accept unforeseeable flare-ups, fatigue, and colds as part of the disease process. As emphasized by Patient 1, outside of being able to achieve the right combination of drugs, there were limited options for managing the effects of RA on lifestyle.

*“I am almost 2 years into it, and other than a brief 3 month stint after I started biologics, this past summer, I have had absolutely no capacity to predict when I’m gonna flare, when I’m gonna be tired, when I’m gonna be sick, and that’s not uncommon and that could be the very nature of the disease. Its unpredictable. And I think...I really think that to be able to manage the fact that you have RA, is to be able to be flexible enough to accept the fact that it’s unpredictable. That you’re gonna wake up one day, and hardly be able to get downstairs. So, is there something that I could do? Sort of getting on the right combination of drugs, I don’t know that there is anything else that I could be doing to manage this better.”* (Patient 1)

*“I think there’s a large component to having to accept the fact that your life was not what it was before you were diagnosed.”* (Patient 1)

Although not physically apparent, the functional disability associated with RA often made it difficult for RA patients to complete daily tasks such as, opening jars or turning doorknobs. A salient adaptation that one participant made to overcome challenges was learning to ask others for assistance through communicating the physical limitations of RA. Potentially, this required a flexible mindset in approaching the situation.

Patient 6 described normalizing her RA symptoms by asking for help and being transparent about the limits of arthritis.

*“Another thing is when there is a perfectly normal thing in your life, and you can’t do it. Sometimes I cannot turn the tap, if it’s closed too tightly, or yesterday I was really struggling with the button on a coat, I couldn’t do the button up, or even until today, I have to wear clothes with snaps. So it’s very, very frustrating, when it’s a perfectly normal thing, like opening bottle of water...”* (Patient 6)

*“...It is really frustrating. The up-side is that I’ve learned to ask for help. So I used to (inaudible) struggle with bottles of water, opening the lid. And then, I just (inaudible) asked the cashier, ‘Can you help me open the bottle of water? I have arthritis’ (inaudible) and now (inaudible) ‘Can you open this for me please?’ (inaudible) so I’m learning how to ask for help...”* (Patient 6)



#### **4.5.2 Improvements through Modifiable Risk Factors**

Given RA pain, inflammation, and side effect management, modifiable risk factors should be considered to improve overall health and quality of life. Modifiable risk factors are often implemented to lower the risk of developing or progressing a chronic disease further. Such modifiable risk factors included physical exercise, diet, sleep, quitting smoking and lowering stress. Participants mentioned RA symptoms were at times difficult to control or anticipate, but areas which can be controlled to improve overall health were worth investing in.

As Key Informant 1 explained, medications helped reduce symptoms to an extent, but modifiable risk factors can also be influential to alter where patients would have a lot of control over lifestyle choices.

*“I mean, you know, there’s a certain level of control you have over your choice of medication and your choice of whether to take it or not, but you know, that’s kind of a...in a lot of ways, that’s a given, where you have influences what you eat, how you sleep, (laughs), what your lifestyle is, what your physical activity patterns are, you know and to the extent that people feel like they can actually improve their health. Um, and their arthritis pain, uh through those methods, I think that just helps improve quality of life overall.”* (Key Informant 1)

Key Informant 2 added that there would be a missed opportunity if RA patients didn’t take advantage of trying to improve modifiable risk factors to better manage their disease.

*“I think, to a certain extent, you can control your outlook about how you live with the disease. So, the physical bits are, you know, always gonna be difficult and you don’t know when it’s gonna show up, and the pain and all of that kind of business. Um, but there is a lot that you can control, and I think that you are doing yourself a disservice if you don’t try and take care of those things.”* (Key Informant 2)

#### **4.5.3 Physical Accommodations**

RA often required oversight on the types of activities and movements to allow or avoid due to its effects on the joints. Physical accommodations included workplace ergonomic changes,

applying grips, minimizing certain movements like pushing and pulling, and opening jars with tools. Over time, RA patients reported learning physical accommodations and adaptations which minimized inflammatory symptoms and fatigue.

Patient 8 described physical workplace accommodations to help with small but repetitive movements which occurred throughout the day at her workplace.

*“Um, that was a big thing um at the beginning because I just could not do it, do anything I mean, my work was very good, I was able to you know, get me new chairs, and put um rubber grips on all of the door handles, and everything like that. And I was able to wear, you know different kinds of slippers to work and everything uh for a couple of years. And it’s just being so tired and in pain all the time and trying to find a different medications that work...” (Patient 8)*

Patient 10 required pushing a cart on the job and noted guarding against joints by learning to push the cart in a different way.

*“With my job, I push a medication cart throughout my day...on linoleum and carpeted floor, so um...that I have to be careful of what I’m doing so I don’t strain the joints and I have RA in. Over the years, I’ve learned how to be careful to push and guard my joints.” (Patient 10)*

Patient 3 mentioned simple daily tasks, such as opening a jar to be the most difficult; however, another way was discovered and compensated for the physical limitations.

*“So, I am reducing my physical abilities to use my hands and arms to do things. But, you do tend to adjust and compensate for that. Things like opening jars are the hardest things. You used to just put your strength into it and just push the jar open; I’ve got wrenches to help me open jars now. So, you do figure out, and you get a book on how to, we’ve got a book on how to cope with rheumatoid arthritis.” (Patient 3)*

For those with flexible work hours and workplace accommodations, taking breaks and napping was an option to combat fatigue symptoms associated with RA. Key Informant 2 described inserting naps throughout the day to increase daily energy levels.

*“Also, um, I’ll often take naps (laughs). On weekends I always take naps, um, sometimes during the weekday, I’ll take naps. But I’m lucky right? Because I work from home for myself, so I can do that kind of stuff. But when I did work, I would sometimes go to a meeting room and nap, um because I was so tired. For me, that’s been a huge part of my disease. Tired, the tiredness. Just like, after a long day of work, I can’t do anything, I can’t do anything else. Like I can cook dinner, that’s kind of it.” (Key Informant 2)*

#### **4.5.4 Self-monitoring**

Self-monitoring technologies and more traditional approaches, such as symptom journaling for chronic disease management, has been a recurring type of intervention to elicit awareness and reflection to better manage symptoms in chronic patients. In our study, symptom monitoring was understood as one type of tool or process to learn how to adapt to the RA lifestyle. Although potentially beneficial to account the symptom changes experienced over time, our findings indicated some caveats for tracking interventions. Some participants saw benefits to seeing patterns on their drug intake and symptom manifestations, whereas others were frustrated at both the lack of actionable intervention to improve the condition and lack of benefit from symptom tracking.

Patient 1 was in favor of data-driven decision making and suggested tracking symptoms, including pain, as it related to medications.

*“But I could have had complete and utter swelling and stiffness three times, prior the week before, and if you’ve actually got a concrete objective record of that, as opposed to the subjectivity of the patient coming in saying, ‘oh I was terrible last week’. I think that would be more useful.” (Patient 1)*

Key Informant 2 explained the frustration behind recording a maximum 10 out of 10 for fatigue severity, and the lack of actionable change; this was an example where having knowledge or awareness of a symptom hadn't translate into something useful.

*“It may be helpful to see like how things have changed for me over time, and I guess, I’m kind of cynical about it, cuz even when I said like you know, here’s my pain in the past week, or here’s my fatigue in the past week, it’s not really like anything’s gonna be done about...like nothing is ever gonna be done about it. I could put 10 for fatigue, every time, like nothing is gonna be done about that.”* (Key Informant 2)

In general, symptom tracking was not effective when there were none to minimal symptoms, or when symptoms occurred infrequently to indicate a noticeable change.

*“Because they don’t come that often anymore, so I don’t feel it’s necessary. I’ll just you know, when I go to the doctor’s, I’ll just say ‘Every now and then’, you know, my thumbs will hurt, or my feet will hurt more, but other than that, no.”* (Patient 8)

Patient 11 expressed that there were some advantages to journaling improvements observed day to day; however, much like other participants, after symptoms improved, monitoring was stopped.

*“Yea, depending on how I felt, I would journal it. At the time, I was starting um (inaudible), and when I started journaling it was before I got the biologic and I was pretty much bed-ridden. And then I started journaling, you know the improvements that I would see day to day. And then ultimately when I was back, mobile again, I got busy and then stopped writing things down.”* (Patient 11)

Key Informant 2 also described not recording morning stiffness and keeping a mental check of it, instead of recording the symptom in a journal or mobile app.

*“...because my symptom changes aren’t so pronounced, there’s not so many of them anymore, I can generally keep a mental check of it, right? So, my morning stiffness again, started over the summer, it was like on and off, it wasn’t regular, um, and within a few minutes, I would be okay so it didn’t last very long. So that’s kind of why, or how I updated him. Um, so just basically by memory. I don’t tend to write things down, or put it in an app.”* (Key Informant 2)

With regards to mobile apps, participants who mentioned using an app were unsatisfied and eventually stopped using it. When symptoms were not well controlled, keeping a diary had helped Patient 11; interestingly, filling in a mobile app for Patient 11 was perceived as one more task to complete.

*“So, I find that to fill in an app just seems to be one more thing to do. I did have a journal for quite a few years when the disease was quite bad. And I did, and I wasn’t overly active, because I wasn’t well-controlled. So, I did keep track in a journal day to day and how I was doing. But, other than that, you know, it was basically I would take each day as it comes when I wake up.”* (Patient 11)

Key Informant 2 described drawbacks of maintaining a diary, which made her focus too much on the disease, and added that the apps she’s tried haven’t been sustained.

*“Um, so sometimes people keep diaries. That way hasn’t worked for me. I haven’t kept like a symptom diary. And I think that’s partly because it makes me focus too much on it, so I tend not to do that. I have a couple of apps, but I actually don’t use them. (laughs). And I’m not sure, again if its like too much work and I cant be bothered, and I’m just lazy.”* (Key Informant 2)

## CHAPTER 5: Discussion

To frame this study, we initially used the 4-step procedural approach defined by Stiggelbout et al. (2015), (Figure 2.1). The definition is largely defined from a physician's perspective for implementing SDM and is incongruent with our findings from an RA patient's perspective of what SDM entails (T2). In many ways, the definition is embedded to work in the existing health care practices and therefore, has also informed the designs of DAs.

Generally, SDM is a sought-after approach in medicine by most patients. However, as the results indicated, misalignment of RA patient needs to the process of Stiggelbout's definition of SDM warrants further discussion. Wider implications are demonstrated as to what chronic RA patients need to be better supported in managing their disease. A qualitative study involving SDM and psychiatric care used Stiggelbout's definition as a framework to understand SDM implementation and found similar results as our study (Rodenburg-Vandenbussche et al., 2019). Patients expressed the need for responsibility over their own bodies which is similar to our data on patient autonomy in (T2); illness severity determined feasibility to engage in SDM, in both our findings (T2) and in Rodenburg-Vandenbussche et al.'s study (2019). Along with SDM, we must also reflect on the intended designs for which DAs are based on and evaluate the extent to which it aligns with RA patient needs. Other than DAs, notable existing technologies include mHealth applications which focus on tracking symptoms (eg. Bant app for diabetes) or monitoring patient reported outcomes and completed lab results (eg. Ned app for prostate cancer).

1. The professional informs the patient that a decision is to be made and that the patient's opinion is important.
2. The professional explains the options and the pros and cons of each relevant option.
3. The professional and patient discuss the patient's preferences; the professional supports the patient in deliberation.
4. The professional and patient discuss patient's decisional role preference, make or defer the decision, and discuss possible follow up.

**Figure 2.2** Procedural Shared Decision Making Definition (Stiggelbout et al., 2015)

### **5.1 Step 2: Options**

Contrary to previous literature (Barton, 2009), patient preferences, such as mode of drug administration, or drug cost were not a primary concern in our study. Rheumatology is routinely focused on clinical indicators of disease severity, pain, and activity of inflammatory joints. Reflective of rheumatology practices, Stiggelbout's definition lacks the prompts needed to discuss health problems outside of physical disability and medications. Secondary impacts of the disease are often present in patients who need to self-manage their chronic disease.

DAs reviewed in Table 2.1 are heavily focused on medication options with the associated side effects which each present with pros and cons. Although Stacey et al. (2014) found that having a DA was better than usual care, most chronic illnesses are multi-faceted; thus, it may be simplistic to conclude that a medication matrix will adequately address RA patient needs.

Instead, our results found priorities in chronic disease management and having a good quality of life with RA. Our study participants frequently mentioned a lack of discussion of psychosocial health concerns affected by their RA (T1). Both mental health and sexual health follow a long-term trajectory where immediate medication side effects, such as fatigue, accumulate over time and play a role in disrupting social and intimate relationships, and limit capacity to endure daily activities. Similar findings related to psychosocial needs among RA care are found elsewhere (Backman, 2006; Pablos et al., 2019).

Additionally, capacity to maintain social obligations is reduced, potentially leading to social isolation as experienced by Patient 8 (T1). Greater attention towards psychosocial aspects of health in patient counseling is needed, specifically with the gap in knowledge, resources, and awareness. Mental health, sexual health, and family planning are psychosocial domains which are sensitive, stigmatized and affect patients long-term. Due to the stigmatized nature of these topics, a general lack of awareness exists among the medical community, RA patients, and general public.

The extent to which physicians should elicit conversations around sensitive topics such as mental health, sexual health and family planning are unclear and context-dependent; however, the chance to be able to address other concerns which affect the RA patients outside of medication choices is an obvious need. The existing fragmented health system presents a challenge in providing holistic health care with adequate care coordination efforts; as such, it is not possible to solve systemic complexity in delivering coordinated holistic health care with DAs, or technology alone. We can only hope to resolve a part of the problem through technology.



The design of a technology to support discussion of options may be to incorporate in-person, or online peer support communities to exchange information and build a community around dealing with sensitive long-term health concerns, especially as our results in T2 found benefit in leveraging on social support networks.

### **5.2 Step 3: Preferences**

Patient agency (T2) is especially important in the context of RA as a chronic illness, but our participants reported that it was not fully recognized, supported, or encouraged in rheumatology visits (T2, T3). Patient agency was not explicitly promoted as part of the discussion, or in the designs of DAs (Table 2.1). This is a challenge since patient agency differs by individual and takes time to develop (T2). Further, patient preferences take time to curate and it is through patient agency that patients develop their own sense of medication preferences and understanding of their health. Patients acquired expertise regarding medication, side effects, adaptations to their lifestyle, and how it affects their body through lived experience. Patient agency is also not supported by DAs (Table 2.1), most DAs confine patient preferences to those listed, and don't provide room for patient input or experiences to be accounted for.

Given that individuals differ in levels of involvement in decision making, perhaps the main takeaway is in providing a means to build patient agency in chronic disease patients. As found in T2, patient agency is a powerful tool which should be used to help patients elucidate their individual values and preferences as it relates to their bodies and lifestyles. Further, the patient's ability to garner social support is a great resource for implementing this part of SDM. We also found valuable insights for how patients seek new knowledge from varied information sources and

how they make personal medical decisions based on their awareness and experience with medications.

SDM could perhaps be better supported if patient agency is encouraged and supported through technology, through systemic changes to the current health care infrastructure, or through alternative support from non-profit organizations. One existing suggestion is to connect newly diagnosed patients sooner to resources, such as the Arthritis Society and CAPA.

### **5.3 Step 4: Decision, Defer, Discuss, Follow up**

Our participants reported that their rheumatology visits were not designed for chronicity and long-term health concerns, or for the patient-physician rapport to be dynamic, to match their changing patient experiences (T3). Further, there are no indications of long term planning, and on-going treatment plans as needed for chronic disease patients. Thus, a missing component of SDM is assisting patients in becoming aware of long-term medication side effects, and addressing health issues presented in T1 which occur dynamically over time. Similar to previous literature (Nota et al., 2015), concerns involving drug toxicity, long-term side effects, and running out of medication options were mentioned in our interviews; perhaps the anxiety associated with long term outcomes need to be better addressed. In a study investigating DA development for diabetes patients, goal setting was an important finding to support, and decision making required flexibility as it was found to be diverse and dynamic (Yu, Ke, Jovicic, Hall, & Straus, 2019). As discussed in Step 2, other health concerns can develop as a comorbidity to RA; for example, depression can also present with fluctuating symptoms over time which needs to be managed in accordance with RA.

RA is a chronic disease where multiple areas of lifestyle are impacted and altered over time to accommodate living comfortably with RA. Due to the changes experienced, there is a need to alter rheumatology visits and to support patients accordingly. The rheumatology visit needs to acknowledge the potential changes in rapport. Decisional role preference may change from when newly diagnosed as a patient (T2) to an expert patient with many years of lived experiences. Resilience and adaptations described in T3 are part of the shared decision-making processes long-term. Adaptations which work provide positive feedback to patients who are struggling to manage their disease and provide value in the shared decision-making process in developing greater patient agency (T2).

Similarly, some DAs display a streamlined series of questionnaires, or provide simplified evidence-based research, and rarely address long term planning. Further, DAs are not designed for chronic patient experiences, which are shown to be important through psychosocial care (T1); the changing patient preferences, or knowledge (T2); changing and learnt adaptations which help to minimize the burden of living with RA (T3); and acknowledgement of monitoring symptoms. Designs of DAs and monitoring technologies should consider accounting for RA as a dynamic disease, as opposed to assuming a set series of needs that may only be applicable for one period in time.

Adaptations are developed and experienced individually; however, due to the lifestyle that RA demands, commonalities exist in how RA patients cope. Thus, there's an opportunity to share adaptations found in T3 to other RA peers who are struggling with similar issues. For example, as found in our study and elsewhere (Kostova, Caiata-Zufferey, & Schulz, 2014), flexibility to

psychological adaptation to the disease by accepting it as a priority is important for those struggling against the disease and trying to retain the lifestyle prior to RA diagnosis.

Living with RA involves change over time and the changes experienced should be reflected in the rheumatology visits to fit RA patient needs as found. Rapport building is context dependent and individualized to the rheumatologist and patient, thus there is no clear way to know how to change or improve these types of patient-physician relationships, other than to recognize that patients may want a different role in their decision making once comfortable managing their disease. Similar findings for changing RA patient-physician dynamics in decision making were found by Mathews et al. (2016).

The extent to which medical professionals, such as rheumatologists, or pharmacists should intervene or have responsibility to address these issues is unclear for on-going chronic disease management issues for lifestyle satisfaction or living comfortably with the disease. The gap in care is in patient counseling and education; and chronic disease management, while some of the adaptations found in T3 are quite personal and up to individual preferences.

## **5.4 Summary**

SDM was initially proposed as a fitting approach to chronic diseases (Joosten, DeFuentes-Merillas, et al., 2008; Montori et al., 2006); however, RA as a chronic disease and its associated comorbidities, as listed in T1, need to be accounted for as part of SDM, rather than solely focusing on weighing options for medications based on evidence-based research. In summary, the Stiggelbout et al. (2015) definition is not flexible enough to incorporate or elicit psychosocial RA patient needs.

Our findings from T1 suggest patient needs for RA-specific care in mental health, sexual health, and family planning, which indicate gaps in knowledge and resources to be addressed. Addressing knowledge gaps is a step towards strengthening patient autonomy and empowerment, contributing to shared decision-making processes. Further, T2 suggests that patient agency provides a basis for RA patients as an active participant in shared decision making. Over time, RA patients developed coping mechanisms and adaptations to their lifestyles, contributing to better chronic disease management, as evidenced by T3.

Psychosocial factors, adaptations, and patient agency are related. For example, having mental health issues with RA symptoms will likely influence patient agency and the need to seek information from different sources, or even consult with a peer with RA. Through iteratively trying to find information and over years, patients develop coping mechanisms through trial and error. These themes are related to the role of shared decision making, decision aids, and RA being a chronic disease. RA is a dynamic disease; patient needs for each person is expected to be different depending on the stage of disease, severity, and life events.

**Table 5.1: Summary of Themes with Recommendations**

<b>Themes</b>	<b>Problem Identified</b>	<b>Recommendations</b>
Psychosocial factors (T1)	Psychosocial factors such as mental health, sexual health and family planning should be included in decision aids and discussed for RA.	Provide an in-person or online support community for chronic psychosocial concerns specific to RA.
Patient Agency (T2)	Patient agency should be supported and built over time.	Prompt skill development for RA lifestyle through developing self-awareness and elicitation of individual values. Connect patients with social network, or help patients develop patient agency earlier on.
Adaptations (T3)	Adaptations to the RA lifestyle is dynamic, complex and lifelong.	Prompt problem-solving skills and share adaptations among RA community through social network to provide support and tips for managing RA changes.

## CHAPTER 6: Conclusion, Limitations, and Future Work

This qualitative study gained an understanding of RA patient perspectives of managing chronic illness; patient needs and views on SDM were explored in relation to the definition by Stiggelbout et al. (2015). Out of the thematic analysis conducted, three main themes were found: *T1) Gaps in Psychosocial Care, T2) Patient Agency, T3) Adaptations*. Contrary to our prior understanding of RA, our findings indicate that RA patient needs extended beyond medication management and DAs need to be designed to address the patient issues found.

### 6.1 Contributions

1. Critically analyzed the SDM definition by Stiggelbout et al. (2015), in the context of chronic rheumatoid arthritis patient experiences.
2. Identified (*T1: Gaps in Psychosocial Care, T2: Patient Agency, T3: Adaptations*) as unaddressed RA patient needs that are important for SDM through thematic analysis of interview data.
3. Suggested how to ameliorate health systems-related constraints which are experienced by RA patients and considerations for DA designs to address the identified needs.

## **6.2 Limitations & Future Work**

### **6.2.1 Analysis**

Our exploratory study had many strengths; however, it is not without limitations. Since the methodology is grounded in patient perceptions of their experiences with rheumatologists, and with managing RA, recall bias is possible. However, rich contextual accounts of patient perceptions and the consistent appearance of similar themes indicated methodologic rigor. Furthermore, our qualitative approach allowed for broad topics to emerge and thus, the results were not limited to predetermined topics of interest. Inherent in latent inductive thematic analysis, interpretation through the lens of the researcher's perspective is also recognized.

### **6.2.2 Sample**

Recruitment of our sample was drawn from the CAPA mailing list, thus there's a possibility that CAPA members may be more informed as a patient than the typical Canadian RA patient because of access to educational patient resources. As displayed in Table 4.1, patient demographics indicate our participants were mainly highly educated and many worked in health care. Moreover, our sample may influence the extent to which participants are able to navigate the health care system and health research. Our analysis provides valuable and rich insight into RA patient experiences, however precautions are taken not to overgeneralize our findings to all Canadian RA participants. Both patients and physicians play a role in medication decision making, but our study did not explore physician perspectives due to time constraints, logistical reasons, and because most SDM studies often included a clinical perspective; thus, we focused on understanding the breadth of patient experiences in order to elucidate RA patient needs in the process of SDM. To contextualize further, though our analysis highlighted valuable insights, another limitation to



recognize may be that SDM is a complex process involving not only patients and physicians, but also multiple factors including: health care policy, staffing and resource shortages, and embedded social norms for medical encounters.

### **6.2.3 Future Work**

This thesis presented work on RA patient perspectives of living with a chronic illness; patient needs and views on SDM were explored in relation to the definition by Stiggelbout et al. (2015). Psychosocial factors, patient agency, and adaptations experienced by RA patients were important needs for SDM to occur. The problem investigated is only one component embedded in the complexity of SDM. Future work should address RA patient needs found in our study using the Interprofessional Shared Decision-Making Model, taking into account micro, meso and macro-level factors. Physicians and their outlook on SDM should also be studied in the realm of RA patients and chronic patient SDM practices.

Patient counseling and education efforts for chronic patients are very important and are under-recognized for RA patients; further endeavors to implement and evaluate programs are needed for RA patients. In particular, psychosocial factors mentioned in our study and daily self-management strategies for RA need greater attention. Patient agency should be encouraged through initiatives to help patients navigate health information, experiential knowledge and organizational communities. Thus, there is still much work to be completed to improve shared decision making processes among chronic patients.

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## **Appendix A1-A4: Approved Research Ethics Material**

### Appendix A1: Interview Guide: For the patient

*Thank you for taking the time to speak with me today regarding shared decision making & decision aids.*

#### General questions

*Collect Demographics: Age: \_\_\_\_\_, Sex: \_\_\_\_\_*

1. At what age were you first diagnosed with RA?
2. How long have you been taking medications for?
3. Which medications do you currently take?
4. Have you had to switch and decide on a different treatment for your RA symptoms?
  - a. If so, any particular reasons why it wasn't working out for you?

#### Part I: The Typical Clinical Encounter

1. Generally, how does the process of treatment consultations look like? Can you think back to your last doctor's visit and can you explain how you and your doctor usually decide on treatment, step by step?
  - a. What are the current ways that you discuss \_\_\_ with your doctor?
    - i. Side effects
    - ii. Medication (incl. available options, type, pros/ cons)
    - iii. Mode of Administration (injection, pill, infusion)
    - iv. Medication interactions / contraindications
    - v. Expected quality of life
    - vi. Other issues patients may be interested in (pain reduction, exercise, work constraints)
    - vii. Medication effectiveness

#### Patient's Perceived Role and Participation

2. What are your main concerns as a patient when deciding on treatment?
  - a. What types of information would be useful if you had access to new scientific info?
  - b. How does RA affect the physical activity you engage in? (ie at work, hobby, sports)
3. Is there something that can be improved that will leave you better informed about your treatment decisions?
4. How do you manage your pain symptoms? Do you keep track of it or monitor it? Does this information play a role when you are deciding on a medication?
5. It's often said that RA patients feel a lack of control over their lives due the pain fluctuations a person can experience. Is there anything that would make you feel more in control of the symptoms?

## Doctors' Perceived Role

6. Does your doctor currently use tools to guide your visits? If so, can you please explain how the tool would be used to discuss medications?
7. Does your doctor ever help you clarify your values for long term or short term goals when discussing medication options?

## Outside of the clinical encounter

8. What types of everyday decision making do you make due to RA considerations outside of the doctors' office?
  - a. Are there any decisions that you would want your doctor to know about?
  - b. Are there certain lifestyle choices that would be helpful if your doctor knew about?

## Part II: Shared Decision Making - instead, explain SDM as an applied ex?

1. Are you familiar with shared decision making (SDM)? If so, can you explain to me what is it to you? (*print out Stiggelbout et al. definition*)
  - a. Do you know if your doctor engages in SDM with you?
  - b. Does your doctor use any decision aids when making decisions on treatment?
  - c. What do you think about SDM? Do you like SDM? /Is it effective?
  - d. Are there parts that you find hard to understand or relate to?
  - e. What are the problems with it, if any?

## Part II Web-based Decision Aid:

1. Would a communication tool on a tablet, compared to a paper decision aid, better guide or inform you and your doctor in the shared decision making process?
2. Any input from the doctor that you wish you received more of? - reword
3. Are there any barriers that you can think of right now to deliver quality SDM?

*Here is a tool created by another student. Do you think that SDM would be supported with this tool? (RA Navigator Tool)*

## Overall interface features (guided)

1. Does it show enough of the right information?
2. Do you think it has enough on here to help you discuss problems about medication choices with your doctor?

*This concludes the end of our interview. Thank you again for agreeing to share your input with us. The results of this interview will be helpful to our research.*

## Print Out for Interview

Definition of Shared Decision-Making as defined by (Stiggelbout et al., 2015)

1. The professional informs the patient that a decision is to be made and that the patient's opinion is important
2. The professional explains the options and the pros and cons of each relevant option
3. The professional and patient discuss the patient's preferences; the professional supports the patient in deliberation
4. The professional and patient discuss patient's decisional role preference, make or defer the decision, and discuss possible follow-up

Shared decision making is where an information exchange and discussion surrounding treatment is made with input from the patient and the doctor, and ultimately, the idea is to come to a treatment decision with patient preferences and medical expertise in mind. Shared decision making, its exactly as it sounds like.



Rheumatoid arthritis medication navigator

- tablet (by mouth)
- injection
- infusion (by vein at clinic)
- Alcohol-friendly
- Generic available (less expensive)
- Safer if in cancer treatment
- Safer for people with heart failure
- Safer for kidney disease
- Safer for liver disease
- Safer for pregnancy
- Safer for tuberculosis

- Methotrexate
- Hydroxychloroquine
- Leflunomide
- Sulfasalazine
- Golimumab brand name Simponi
- Adalimumab brand name Humira
- Certolizumab brand name Cimzia
- Etanercept brand name Enbrel
- Rituximab brand name Rituxan

basic issues | **RA improvement** | pain | work | side effects

### How well do these medications work?

It turns out that's a tough question. There are dozens of ways to ask how much someone with RA has improved by taking a medication—from just asking, to lab tests, to X-rays.

One way is to have a doctor count tender and swollen joints, and ask people about their pain or overall assessment. If there's 50% improvement, that is generally considered good progress.

50% improvement for people taking ...by about 6 months ...by about 1 year ...by about

Methotrexate  
+ Sulfasalazine  
+ Hydroxychloroquine  
+ Prednisolone

42 people out of 100 would be expected to experience 50% improvement  
source randomized trial  
quality

no research that looked into this at 1 year  
no research

As part of the interview, a digital decision aid prototype, RA Navigator was shown to provoke discussion around decision aids.

## Appendix A2: Recruitment Email

This email is being sent on behalf of the researchers.

Hello,

My name is Marina Wada and I am a Masters student working under the supervision of Dr. James Wallace in the IDEA Lab in the Applied Health Sciences Faculty at the University of Waterloo.

I am contacting you through the Canadian Arthritis Patient Alliance because I am looking for volunteers who would be interested in participating in a study on rheumatoid arthritis and decision aids. I am seeking volunteers who are diagnosed with rheumatoid arthritis and are willing to participate in a study which focuses on use of an online decision-making tool to improve communication and conversations around RA treatment options. This research will hopefully lead to a better understanding for designing decision aid tools for RA patients and rheumatologists, and eventually be used in clinical visits.

If you volunteer as a participant in this study, you will be asked to answer a set of interview questions verbally, interact with the decision aid, and give us feedback about the decision aid. In addition, this interview will be conducted online through Skype. With your permission, this session will be audio-recorded. These questions are related to your perceptions of shared decision-making when deciding on a treatment option. In order to participate in this study, you must be diagnosed with rheumatoid arthritis. This study will take approximately 45 minutes of your time. In appreciation for participating in the study we will provide you with a \$10 gift card.

I would like to assure you that this study has been reviewed and received ethics clearance through the University of Waterloo Ethics Committee. However, the final decision to participate is yours.

If you are interested in participating or would like more information about this study, please contact me at [mwada@uwaterloo.ca](mailto:mwada@uwaterloo.ca). I will then schedule you in and send a confirmation email indicating that you have been signed up, along with an information letter and consent form. If you have to cancel your appointment, please email me at [mwada@uwaterloo.ca](mailto:mwada@uwaterloo.ca).

Sincerely,

Marina Wada

MSc in Public Health and Health Systems (Candidate)

School of Public Health and Health Systems | University of Waterloo|

E: [mwada@uwaterloo.ca](mailto:mwada@uwaterloo.ca)

## **Appendix A3: Information Form and Informed Consent**

### Evaluating User Needs: An Exploratory Study on Decision Aids for Rheumatoid Arthritis Patients and Physicians Engaging in Shared-Decision Making

#### Information Form & Informed Consent

This study is conducted on behalf of researchers at the University of Waterloo. The principal investigator is Dr. James Wallace from the School of Public Health and Health Systems at the University of Waterloo, assisted by Student Investigator, Marina Wada.

The purpose of this study is to understand user needs that would better facilitate shared decision making practices between rheumatoid arthritis patients and physicians. In this study, we will collect your feedback on how you interact with your physician, and how the Rheumatoid Arthritis (RA) Navigator as a technology and decision aid tool may help in the process of communication when deciding on a treatment. It is expected that overall, this study will provide us with critical information on whether interaction between patients and physicians would improve with the use of the electronic decision aid in a clinical visit. This work is an important first step in understanding the users of the RA Navigator as an iterative step towards a better design. Furthermore, this study aims to address a communication gap that exists in the health care system.

If you choose to participate in this research study, you will be asked to sign an informed consent. You will then be asked about your demographic information such as age, sex, age at diagnosis and current medication you are taking. Next, you will be asked to think back to the last time you were in a doctor's office for RA medications or symptoms. You will then be asked to verbally answer a set of interview questions about the visit, how treatment decisions were made, and how side effects, medication types, expected quality of life, and medication complications were discussed. You will then be asked about your perceptions of a shared-decision making when deciding on a treatment option. You will have the opportunity to interact with the digital decision aid, which was designed to help patients understand treatment options for RA. We will then seek feedback from you regarding the decision aid. You may be asked to explain your responses to some questions by the interviewer.

This study will take about 45 minutes to complete. In appreciation for participating in the study we will provide you with a \$10 gift card. The amount received is taxable. It is your responsibility to report this amount for income tax purposes.

Participation in this study is voluntary. Interviews will be held face-to-face online through Skype. You may decline to answer any of the question(s) on questionnaires or posed by the interviewer if you wish. Further, should you decide to withdraw from the study, you can withdraw your data up to one month after your interview.

With your permission, the entire session which contains the interview session will be audio recorded to facilitate collection of information, and later transcribed for analysis. Your identity will be confidential. We will publish the anonymized data from this study. Examples of anonymized data would be the use of a participant ID in place of the participant's name. Personal identifiers, such as your name will not appear in any thesis or report resulting from this study, however, with your permission anonymous quotations may be used. Nothing in the published dataset would identify you specifically. There are guidelines for publishing safe, anonymized data and the researchers will be following these.

When information is transmitted over the internet, privacy cannot be guaranteed. There is always a risk your responses may be intercepted by a third party (e.g., government agencies, hackers). University of Waterloo researchers will not collect or use internet protocol (IP) addresses or other information which could link your participation to your computer or electronic device without first informing you.

If you prefer not to participate using this online method, please contact one of the researchers so you can participate using an alternative method such as a telephone call. The alternate method may decrease anonymity but confidentiality will be maintained.

Data collected during this study will be retained for at least 7 years in a locked office in my supervisor's lab. Only researchers associated with this project will have access. There are no known or anticipated risks to you as a participant in this study.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE# 22573). If you have questions for the Committees contact the Chief Ethics Officer, Office of Research Ethics, University of Waterloo at 1-519-888-4567 ext. 36005 or [ore-ceo@uwaterloo.ca](mailto:ore-ceo@uwaterloo.ca). For other questions, Professor James Wallace at 519-888-4567 x 30184 or email [james.wallace@uwaterloo.ca](mailto:james.wallace@uwaterloo.ca).

If you have any questions regarding this study, or would like additional information to assist you in reaching a decision about participation, please contact me at by email at [mwada@uwaterloo.ca](mailto:mwada@uwaterloo.ca). You can also contact my supervisor, Professor James Wallace at 519-888-4567 x 30184 or email [james.wallace@uwaterloo.ca](mailto:james.wallace@uwaterloo.ca).

I hope that the results of this study will be of benefit to those organizations directly involved in the study, other groups or associations not directly involved in the study, as well as to the broader research community. I very much look forward to speaking with you and thank you in advance for your assistance in this project.

Yours Sincerely,

Marina Wada

Consent of Participant

*By signing this consent form, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.*

I have read the Information Letter regarding the study being conducted by James Wallace and Marina Wada of the School of Public Health and Health Systems at the University of Waterloo. I have had the opportunity to ask questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted.

I am aware that I have the option of allowing my interview to be audio recorded to ensure an accurate recording of my responses. I am also aware that excerpts from the interview may be included in the thesis and/or publications to come from this research, with the understanding that the quotations will be anonymous.

I was informed that I may withdraw my consent up to one month after the interview without penalty by advising the researcher.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE# 22573). If you have questions for the Committees contact the Chief Ethics Officer, Office of Research Ethics, University of Waterloo at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca. For other questions, Professor James Wallace at 519-888-4567 x 30184 or email [james.wallace@uwaterloo.ca](mailto:james.wallace@uwaterloo.ca).

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

YES  NO

I agree to have my interview audio recorded.

YES  NO

I agree to the use of anonymous quotations in any thesis or publication that comes of this research.

YES  NO

Participant Name: \_\_\_\_\_ (Please print)

Participant Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Witness Name: \_\_\_\_\_ (Please print)

Witness Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## Appendix A4: Feedback Letter

### FEEDBACK LETTER

Project Title: Evaluating User Needs: An Exploratory Study on Decision Aids for Rheumatoid Arthritis Patients and Physicians Engaging in Shared Decision-Making

Faculty Advisor: Jim Wallace, School of Public Health and Health Systems, [james.wallace@uwaterloo.ca](mailto:james.wallace@uwaterloo.ca), x30184

We appreciate your participation in our study, and thank you for spending the time to help us with our research!

The purpose of this study was to understand patient needs and physician needs to enable better shared-decision making communication practices during a clinical visit in order to improve the design features of the decision aid tool, the RA Navigator.

In this study, we collected your feedback on how you currently interact during a clinical visit, what you think the process should ideally look like, whether you would use technology in a clinical encounter, and which features on the tool may improve shared-decision making during visits.

It is expected that overall, this study will provide us with critical information on the types of features on a tool that would help enable better communication and decision making between patients and physicians during a clinical visit. The idea is to empower patients by informing them of disadvantages and advantages comparatively across different RA treatment options, and have the tool as a basis to spark conversation about difficult treatment decisions with the physician. This work is an important first step in improving decision support tools for chronic illnesses as a long term goal. Our next goal is to implement the results into the tool to further improve and test the tool during a next iteration.

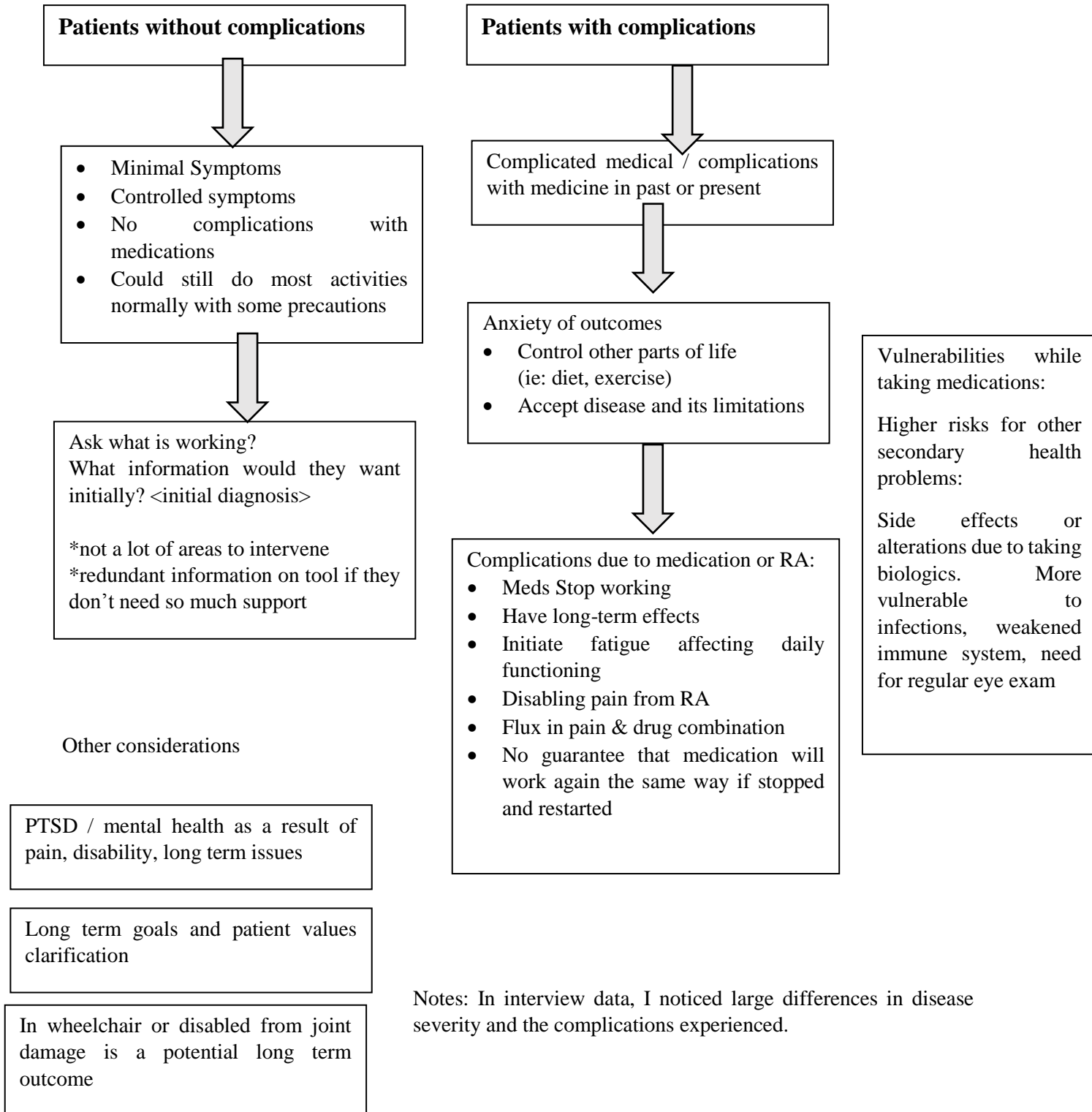
Further, should you decide to withdraw from the study, you can withdraw your data up to one month after your interview. Your identity will be confidential. We will publish the anonymized data from this study. Personal identifiers, such as your name will not appear in any thesis or report resulting from this study, however, with your permission anonymous quotations may be used. Electronic data, paper records, and audio recordings collected during this study will be retained for at least 7 years in a locked office in my supervisor's lab, to which only researchers associated with this study have access to.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee. If you have questions for the Committees contact the Chief Ethics Officer, Office of Research Ethics, University of Waterloo at [1-519-888-4567 ext. 36005](tel:1-519-888-4567) or [ore-ceo@uwaterloo.ca](mailto:ore-ceo@uwaterloo.ca). For all other questions, please do not hesitate to contact Professor Jim Wallace at [james.wallace@uwaterloo.ca](mailto:james.wallace@uwaterloo.ca) or Ext. 30184.

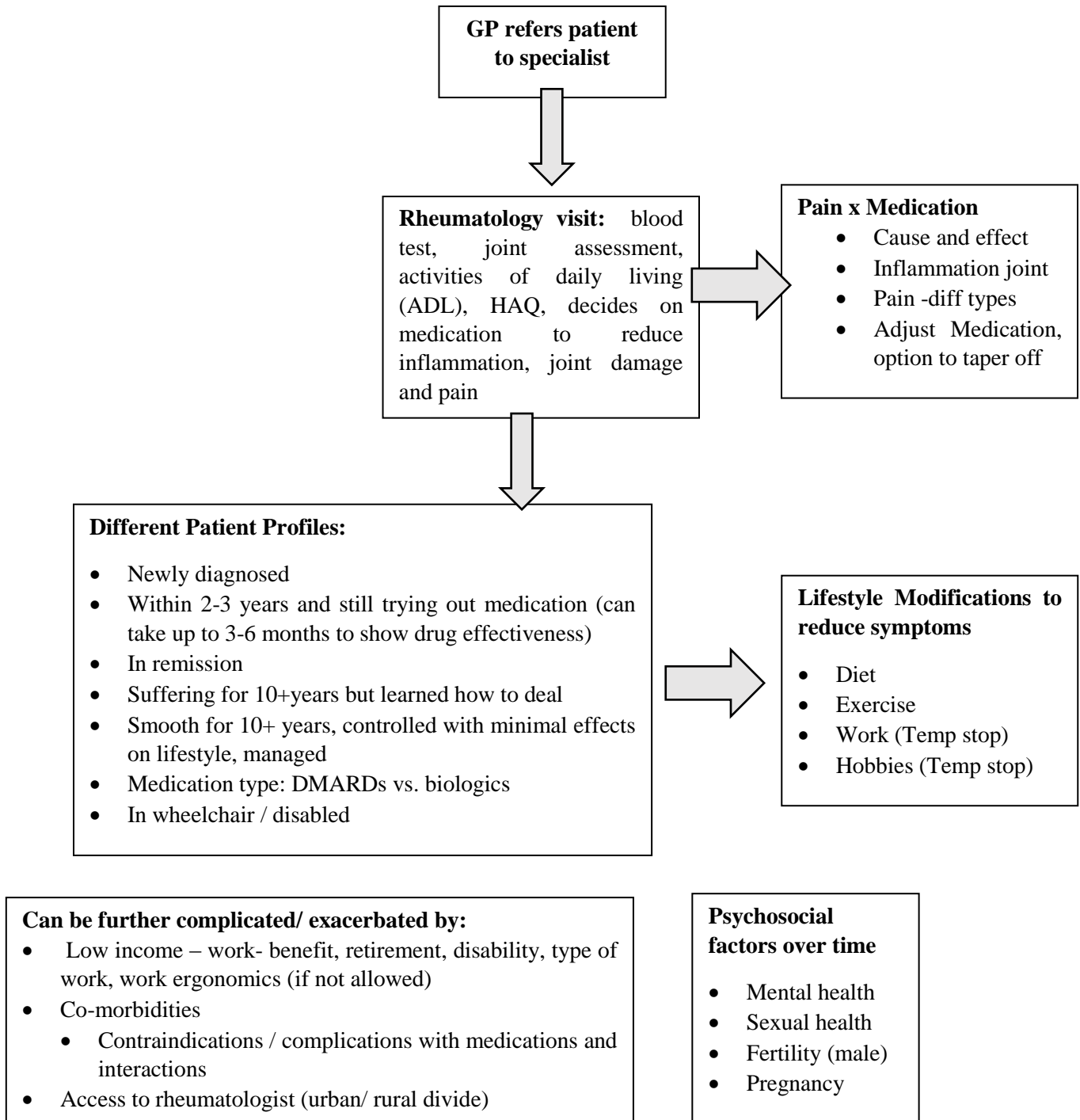
We really appreciate your participation, and hope that this has been an interesting experience for you.

## Appendix B1-B3: Thematic Mapping

### Appendix B1: Thematic Mapping of Phase I Different RA Patient Types



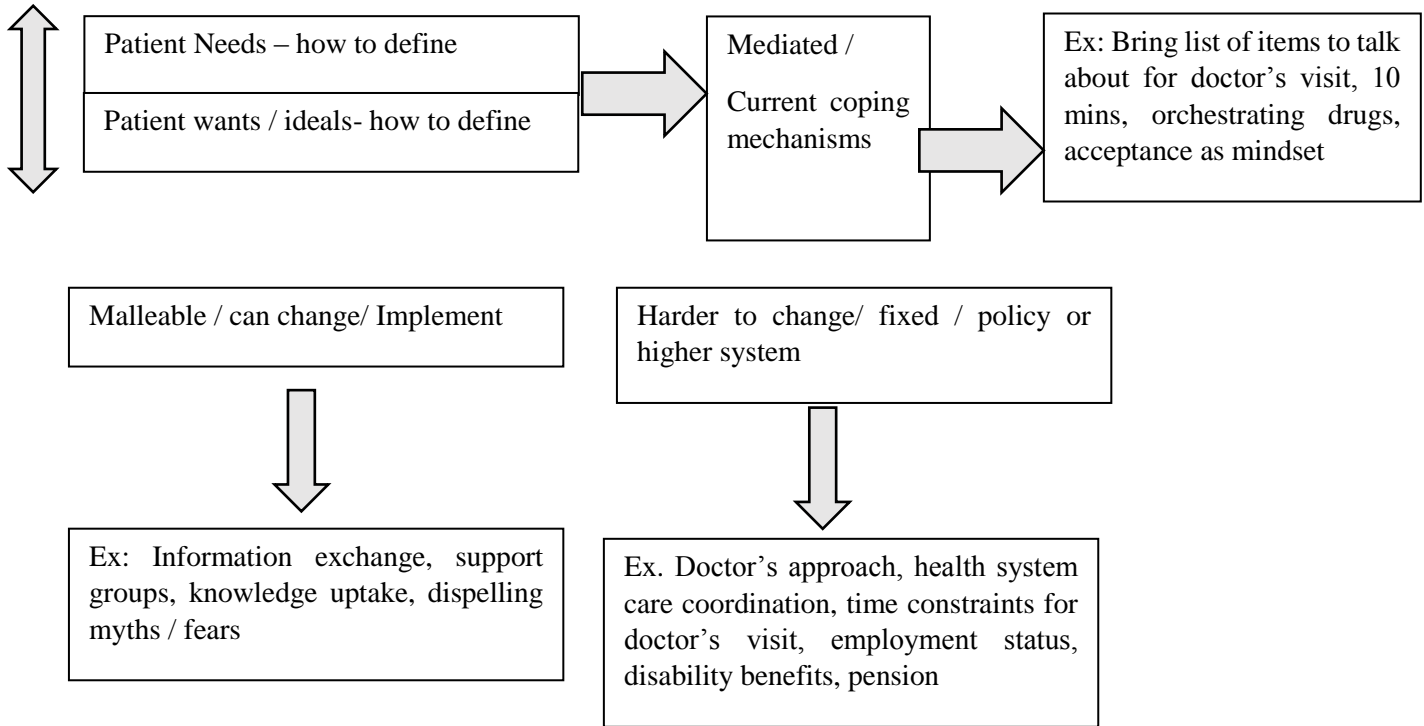
**Appendix B2: Thematic Mapping of Phase II**  
 Patient Experience Journey of Navigating the Health System.



Notes: Most RA patients go through similar standard rheumatology procedures that focus on pain, inflammation and medications. However, various patient profiles exist demonstrating the diversity of cases. Other boxes show factors that can worsen or improve conditions. Chronic co-morbidities can develop over time along with RA.



**Appendix B3: Thematic Mapping of Phase III**  
 Shared Decision-Making Given Time Constraints



Notes:

Time is limited during doctor’s visit for shared decision-making. Very rarely will a patient have more than 10 minutes of time during a doctor’s visit. Knowledge tool may be better suited, or a DA that is tailored to each specific patient at differing stages of disease.